WHEELCHAIR USERS AND HOUSING IN DUNDEE: THE SOCIAL CONSTRUCTION AND SPATIALITY OF DISABILITY

Susan L. Levy

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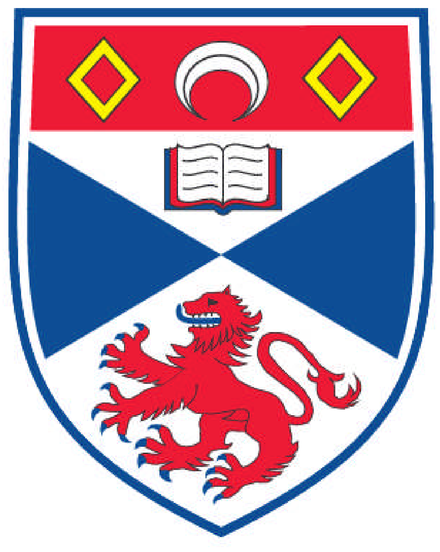

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Abstract

The thesis examines the experiences and perceptions of wheelchair users living in different types and tenures of housing in the City of Dundee. The interrelationships between space, society and the body are examined in the empirical context of housing, ableism and the disabled body. The voices of wheelchair users, gleaned from in-depth, semi-structured interviews, are used throughout the thesis to illustrate how the geographies of people with disabilities are delineated and constrained by socio-cultural representations of disability. Conceptually the study has been guided by the social model of disability, but insights from postmodernism and feminist literature are drawn on to add a further dimension to the interpretation of the data and the study's methodology. The social construction of difference, social exclusion and definitions of the normal and aberrant body emerge as key concepts linking analysis of the data at the spatial scales of the neighbourhood, home and the body. Spatial metaphors of 'out of place', 'marginalised' or 'socio-spatially excluded' capture the essence of the impressions people with disabilities hold of their interactions with their living spaces and service providers. The study suggests that greater reciprocal dialogue is required between service users and service providers to broaden the knowledge base from which disability related housing decisions are made.

Declaration

i) I, Susan Louise Levy, hereby certify that this thesis, which is approximately 91,000 words in length, has been written by me, that it is the record of work carried out by me and that it has not been submitted in any previous application for a higher degree.

Date 20/10/01... Signature of candidate ..Susan Levy.....

ii) I was admitted as a research student in October 1995 and as a candidate for the degree of Ph.D. in October 1996; the higher study for which this is a record was carried out in the University of St Andrews between 1995 and 2001.

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List of abbreviations

DCC	Dundee City Council
HA	Housing Association
LA	Local Authority
MBHA	Margaret Blackwood Housing Association
OT	Occupational Therapist
SH	Scottish Homes

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INTRODUCTION

Geographical interest in disability has burgeoned over the last decade as the socio-spatial theorising of people with disabilities has caught the imagination of social and cultural, and health geographers. At the start of the 1990s the work of the behaviouralist geographer Golledge (1991,1993), on tactical mapping for the visually impaired, was unique in the discipline. There is now a growing theoretical and empirical literature on disability as a social construct, evidence of which lies in numerous papers and texts (Butler and Parr, 1999; Gleeson, 1999; Imrie, 1996a), special sessions at national and international geography conferences (IBG, 1997; CAG, 2000), sub-sections on disability in social geography teaching texts (Knox and Pinch, 2000), and a definition of disability appearing in geographical dictionaries (Johnston, *et al.*, 2000; McDowell and Sharp, 1999).

Interest in the social theorising of disability has emanated from the work of sociologists and the development of the social model of disability (Oliver, 1990a), to which geographers have added a spatial dimension. Geographical concerns with disability also stem from wider theoretical developments within the discipline, principally postmodernist and feminist literature and the challenge they have posed to the logic of a singular, Marxist, class based understanding of social differentiation (Jackson, 2000). This literature has exposed a wider range

of human differences associated with socially constructed notions of gender, race, sexuality and latterly, disability. Geographers have used spatial metaphors to illustrate how social differences are experienced and represented within and between spaces and places, centres and margins. In doing so they have demonstrated that differences are situated and produced socio-spatially; that is, they are produced in relation to prevailing social discourses and axis of power that produce social space (Lefebvre, 1991; Soja, 1989), and delineate spatially the inclusion or exclusion of social groups in society. This recursive relationship between society and space is dependent on a third factor that has concerned feminist and postmodernist geographers over recent years: the body, and how different bodies are represented and experienced in socio-spatial interactions. Recent interest in the unique geographies of people with disabilities coalesces around these theoretical advances and offers an insight into how social spaces and disability are produced by a discourse of ableism that, consciously or unconsciously, marginalises people with disabilities based on their bodily differences.

The practices of ableism are evident in social policies and society's attitudes towards disability, but are most apparent in the design of the built environment, including the design of houses. Socio-cultural understandings of disability can be gleaned from both the inaccessibility of mainstream housing and the accessibility of special needs housing. Special needs housing for wheelchair users, whilst designed to be accessible, is also perceived to be different from mainstream housing in representing spatial manifestations of prevailing social

attitudes towards disability; towards people whose bodies are socially constructed as falling outwith established cultural norms.

Both special needs and mainstream housing have been used in this thesis to explore how disability is produced and experienced as a socio-spatial phenomenon, and to understand how barriers are constructed that exclude people with disabilities as the Other from entering and participating fully in the spaces of the able-bodied, the spaces of the same. The recursive relationship between space, society and the body, is examined in the empirical context of housing, ableism and the disabled body, using data gleaned from fifty in-depth, semi-structured interviews with wheelchair users, aged between 16-64 years, living in different types of housing and tenancies across the city of Dundee. The interviews were designed to elicit the difference disability makes to people's lives and the differences between people with disabilities[1] through addressing the following two study objectives. First, investigating the social and physical barriers associated with wheelchair users housing in the city of Dundee. Secondly, examining the significance of place to individuals' identity and experience of social inclusion or exclusion. The underlying causes of marginalisation experienced by people with disabilities in relation to their housing are examined by moving beyond the narrow confines of the bricks and mortar of wheelchair users' housing. Discussion is extended to incorporate consideration of how the local geographies of people with disabilities are curtailed and delineated by place based (physical and social) barriers in and around their homes. The social construction of difference, the normal and abnormal body and social exclusion are key themes linking the emerging patterns

of marginalisation experienced by people with disabilities at the spatial scales of the neighbourhood, the home and the 'geography closest in' (Rich, 1986:212): the body.

My initial interest in the physical accessibility of different spaces derived from my experience, as an able-bodied mother, of trying to negotiate inaccessible environments with a pram or a push-chair. There are superficially similarities in the experiences of wheelchair users and mothers pushing small children in push-chairs in physically inaccessible spaces: however carers of small children can potentially overcome physical barriers, push-chairs can be folded down and small children and babies carried up and down steps or onto public transport. The same is not true for adult wheelchair users with large, cumbersome wheelchairs. The social barriers that mothers and wheelchair users encounter are also markedly different and reflect society's perceptions and acceptance of these two social groups. It is the interface between disability, society and space that is the kernel of this study.

The thesis begins (Chapter 2) by contextualising the study in the theoretical literature that has informed a socio-spatial understanding of the construction of disability, and the logic that shapes the hegemony of ableism. The following chapter (Chapter 3) looks at ways of researching disability through an examination of the methodological and epistemological foundations of the study, and the methods used for representing and giving a voice to the Other. Chapter 4 traces the history of housing for people with disabilities as attempts to deal with the inaccessibility of mainstream housing led to the development of ostensibly

accessible special needs housing. Problems with specific design features reveal the insensitivity and standardisation of ableist design. The chapter closes by suggesting that recent legislation requiring all new houses to be built to barrier free standards heralds the long term potential of accessible housing becoming the norm. Chapter 5 focuses on a specific type of special needs housing, sheltered housing, and exposes the exclusion and stigma people living in sheltered housing (insiders) encounter from their neighbours, predominantly older people, and from people with disabilities living in non-sheltered housing (outsiders), respectively. Attention is shifted in Chapter 6 to the accessibility of housing information from service providers (second hand knowledge), and the power service users have to utilise their first hand knowledge to exercise choice and control over their housing decisions. The chapter reveals that greater reciprocal dialogue is required between service providers and users to empower the latter. Chapters 4 to 6 illustrate how the impaired body is constituted by and through space and prevailing social discourses, and in a cyclical process, how representations of the body are inscribed onto space. The penultimate chapter focuses exclusively on the body to illustrate that an understanding of how different bodies are produced socio-spatially unlocks a wealth of information about the production of social spaces as accessible or inaccessible, as inclusive or exclusive. The chapter extends debate on socio-cultural representations of the body to include physical embodiment, the pain, fatigue and immobility that accompanies physical impairment. It reveals how both physical embodiment and social embodiment curtail the use of public spaces by wheelchair users.

The thesis aims to contribute to geographical understanding of how disability is constructed in different social spaces through an empirical demonstration of how social space can both enable and/or disable people with disabilities. It illustrates the need for greater understanding and awareness in able-bodied society of what it means to be disabled by a society that is predominantly constructed by and for 'normal' able-bodies. It is the purpose of this research to help demystify the concept of 'disability' and challenge established misperceptions of the life courses and life experiences of people with disabilities.

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[1] A brief note on terminology and my use of 'people with disabilities', rather than 'disabled people'. The former term has now been adopted in most Western countries as a more humanising term than disabled people. It emphasises the individual person over their disability, and is therefore, Gleeson (1999) states, seen as supporting the general quest for cultural respect and equal rights by people with disabilities. However, Gleeson (1999) and others (see Morris, 1993) choose to retain the term disabled people in their work believing it 'serves a political purpose by foregrounding the oppression – in other words, the socially imposed disability – that bears down upon impaired people' (Gleeson, 1999:9). Despite Gleeson's (1999) convincing argument for using the term disabled people, I use the term people with disabilities in this study.

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THEORETICAL CONTEXT OF STUDY

INTRODUCTION

Traditionally health has been studied within the field of medical geography, a sub-discipline of human geography. Within this field the generic term health has been defined bio-medically and used to refer to ill-health. Dorn and Laws (1994) argue that medical geography's understandings of health and illness have been restricted by understanding 'the body as a site invaded by disease with a specific aetiology' (Dorn and Laws, 1994:107). Over the last decade there has been increasing concern with what Kearns and Joseph (1993) have described as unproblematised 'geometric space' in medical geography. With 'geographers noting that space cannot adequately be conceived of as a mere blank surface on which uncritically to map medical and "deviant" subjects' (Parr and Philo, 1996, cited in Parr and Butler, 1999:11). These concerns have led to medical geography experiencing what has been termed a 'cultural turn' (Parr, 1999) 'in which contested geographical concepts such as landscape and place have been critically evaluated in relation to therapeutic processes and spaces, notions of ill-health and relations of power' (Parr, 1999:120). The subsequent shift from medical geography towards a new geography of health is symbolised in a move away from the description and mapping of ill-health to a critical engagement with place and the body (impaired and ill, as well as healthy and able-bodied).

Feminist literature has contributed to the emerging field of health geography by introducing a new sensitivity towards the body in critical studies which focus on how different bodies experience health, place and embodiment. These shifts in the focus and content of health geography have stimulated studies on the intersections between place, bodies, health and identities in everyday geographies and promoted work on geography and disability.

In under a decade the geographical literature has moved from being a 'wasteland' (Chouinard and Grant, 1995)[1] with regard to published work on disability, to experiencing a significant growth in academic papers in the sub-discipline. There are now five discernible approaches to the study of disability within geography (Imrie, 2000), and I want to provide a short summary of each.

First, scholars working within the discourse of the bio-medical model sit within traditional medical geography where disability is conceived of as a disease and is studied by, for example, epidemiological mapping exercises of disease (see Jones and Moon, 1987). The geography of people with mental health problems is a second approach to the study of disability. The work of Dear and Wolch (1987) on deinstitutionalisation has been influential in this area highlighting societal attitudes towards deviant bodies and the practices of spatial segregation and exclusion.

A third approach is offered by the work of behavioural geographers, for example, Golledge (1993) has been particularly significant here. Arguing that the 'disabled live in a transformed space' (1993:64) where obstacles and barriers are

magnified many times, Golledge has drawn attention to the skills geographers can bring to developing accessible maps, navigational aids and other technical devices to assist people with vision impairments to navigate their way through otherwise inaccessible spaces. Critics of Golledge (see Gleeson, 1996; Imrie, 1996b) suggest that his approach is descriptive and reductionist, linking the negative experiences of people with disabilities to their individual impairments.

This critique of Golledge's work is addressed in the fourth approach to the study of disability, that is a social constructivist perspective that has its roots in historical materialism. Gleeson (1999) and Imrie (1996a) have contributed to an understanding of disability as being produced by different societies and spaces, and have thus shown geography to be 'a constitutive part of disabled people's oppression and marginalization in society' (Imrie, 2000: 179). In a significant contribution to this debate, Chouinard (1997) has used the concept of ableism. Ableism is used to refer 'to ideas, practices, institutions and social relations that presume ablebodiedness, and by so doing, construct persons with disabilities as marginalised, oppressed, and largely invisible "other's"' (Chouinard, 1997:380). She goes on to define ableist geographies as 'lived environments which incorporate and perpetuate physical and social barriers to the participation of disabled persons in everyday life' (Chouinard, 1997:380).

Finally, the fifth approach to the study of disability is characterised by the use of feminist and postmodernist literature to explicate how disability is a form of socio-cultural differentiation like gender, class, race and sexuality, and to expose the differences between people with disabilities. The work of Butler and Bowlby

(1997) and a recent edited collection of papers by Butler and Parr (1999) illustrate these recent theoretical developments in the sub-discipline. The work of these authors has highlighted the heterogeneity of people with disabilities by moving beyond dualistic thinking whereby disability is defined as either a medical condition or a social construct. This literature develops the linkages between physical and social embodiment, between biology, place and wider socio-economic and political relationships. It is this last approach along with the social constructivist perspective on disability, and to a lesser extent the work on the spatial segregation of exclusion, outlined above that have informed this study.

Despite this growing interest in the geographies of disability, the field remains relatively neglected and peripheral within geography. Chouinard and Grant (1995) insist that geographers' continued neglect of people with disabilities is restricting their understanding of the landscape of late capitalist societies. It is the argument of this thesis that, in a discipline where the raison d'être is the interaction between the spatial and the social, the geographical imagination must make space for including people with disabilities in its understanding of the inter-relationships between society, space and different bodies. It has been an objective of this study to help fill this lacuna in the geographical literature on disability by contributing to the emerging body of knowledge on geography and disability. The objective of this specific chapter is to provide an overview of the theoretical foundations upon which this study has been built and the concepts and literature that have guided the research. The chapter opens by discussing the social model of disability and a social constructivist account of disability

introduced into disability studies by sociologists. The chapter moves on to outline how an understanding of social space is contributing to theorising disability. These initial two sections are elaborated on in the subsequent sections on disciplinary power, oppression and normalisation, to illustrate how the processes of power and discourse produce and subsequently reproduce social imagery that constructs certain bodies as normal and others as abnormal. The principal concepts of the social model of disability: that people are disabled by physical and social barriers in their living spaces, are the focus of the next two sections. The first considers physical barriers in monofunctional and multifunctional designs, and the second looks at social barriers created through stigma and people's perceptions of different bodies. The final section explores the literature that has critiqued the social model of disability for failing to incorporate physical impairment into theorising disability, when, it is argued, it impacts on people's geographies irrespective of physical and social disabling barriers.

THEORISING DISABILITY

Disability studies emerged as a coherent discipline in the 1950s (Gleeson, 1999). The early studies in the discipline were principally a discourse on policy issues, such as employment, physical access, benefit rights and deinstitutionalisation, but as Gleeson (1999) argues, they were largely atheoretical. The history of undertheorising within the discipline can be traced to the failure of the social sciences generally to consider physical impairments as an important issue. This is related to 'the wider problem of entrenched indifference of social science to

issues of human embodiment' (Gleeson, 1999:16). The legacy of a theoretical imbalance in the discipline is in the process of being corrected as the study of disability begins to define and carve out a niche for the social theorising of disability. Certainly the late 1980s and 1990s experienced a burgeoning interest in and papers on the social theorisation of disability, largely by disabled academics (Abberley, 1993; Hahn, 1989; Oliver, 1990a, 1992, 1996; Shakespeare, 1994). Up to this point people with disabilities had been defined by a bio-medical discourse as 'individual medical tragedies' (Shakespeare, 1993) in which the body was conceptualised as failing to meet socio-cultural standards of normality, in physical ability and mobility.

The medical model of disability is used to define thinking that conceives of disability as an individual problem, something that needs to be treated medically and requires social support, care, sympathy and charity. Disability in the discourse of the medical model is situated 'in the individual's supposed deficiency and her or his personal incapacity's when compared to 'normal' people' (Abberley, 1997:1). The following classification of impairment, disability and handicap, adopted by the World Health Organisation (WHO) in the 1970s, is illustrative of the discourse of the medical model of disability.

- Impairments are defined as 'disturbances in body structures or processes which are present at birth or result from later injury or disease'.
- Disabilities are 'limitations in expected functional activity or as restrictions in activity due to an underlying impairment'.
- Handicap results from, 'difficulties in performing activities of daily living, like walking' (Wood 1981:54)[2].

The use of these definitions by an influential, global organisation like the WHO has led to this terminology being assimilated and used by state governments to

inform policies and practices around the world. There is no mention in the WHO definitions of how society does and can disable people with impairments. This is of particular concern to disability scholars when so much of their work is political and demands 'explanations that lead to policy prescription and material change' (Gleeson, 1999:17). Parr and Butler (1999) argue that the medical model of disability has its origins in the rise of medical science and has been used as a mechanism by which people with bodily differences have been categorised and accommodated by Western society.

> 'The medical model of disability is one rooted in an undue emphasis on clinical diagnosis, the very nature of which is destined to lead to a partial and inhibiting view of the disabled individual. In order to understand disability as an experience, as a lived thing, we need more than the medical 'facts' ... The problem comes when they determine not only the form of treatment (if treatment is appropriate), but also the form of life for the person who happens to be disabled.'
>
> Brisenden, 1986:173, cited in Parr and Butler, 1999:3)

When the medical model was seen to be serving to perpetuate the oppression experienced by people with disabilities in society, rather than seeking to annul it, the hegemony of the model began to be eroded. Changes in theoretical thinking, or 'paradigm shifts' (Kuhn, 1961), occur when there is growing recognition that present ways of thinking no longer conform to the prevailing dominant paradigm. The emergence of the social model of disability, as a competing paradigm to the medical model, developed from the realisation that the number of anomalies in the medical model rendered it redundant as a framework for understanding the lives and aspirations of people with disabilities. The emerging literature that conceived of disability as a social construct was critical of the ideas and practices of medicalisation, and represented an important departure from the prevailing

disability discourse of defining disability as a 'personal tragedy' (Finkelstein, 1980; Oliver, 1990a).

Social Model of Disability

The 'revolutionary' (Crow, 1996) approach to understanding disability as a socially constructed phenomenon began in an anthology of essays on disability edited by Hunt (1966). The work of many of the contributing authors, who were themselves physically impaired, cumulated in the Union of Physically Impaired Against Segregation (UPIAS). This was a newly formed group of people with disabilities who, after meeting regularly to share their experiences and further their personal struggles collectively, came to the conclusion that disability was a form of social oppression, which they distinguished from physical impairment (Oliver, 1996).

> 'In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called 'disability', of people with such an impairment. Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression'.
>
> (UPIAS 1976: 3-4).

The founding members of UPIAS posited a clear distinction between physical impairment as a *description* of a medically defined condition, and disability as a

process constituted and controlled by the interaction of economic and social structures with physical impairment (Finkelstein, 1980). The creation of the binary division between physical impairment and disability by the UPIAS parallels the sex/gender dichotomy in feminist literature, which likewise distinguishes between biological capabilities and socially produced characteristics and inequalities (Butler & Bowlby 1997). It also reflects a broader movement within the social sciences literature away from theories that have explained social differences as reflections of nature (of biological determinism) towards social constructivist accounts of gender, race, sexuality and more recently disability.

Oliver (1983) transformed the UPIAS ideas into what is now understood to be the social model of disability. He developed the foundations of a historical-materialist approach to disability arguing that the medicalised and tragic view of disability (the medical model) was unique to capitalist societies (see Oliver, 1996: 32). The social model drew attention to how broad economic structures of society can be implicated in creating disability 'by devaluing bodies that do not straightforwardly conform to the time-space work regimes of capitalist society' (Parr and Butler, 1999:4, see also Barnes, 1991; Oliver, 1990a; Shakespeare, 1993; Swain et al., 1994). Under capitalism all phenomena (including social categories) are produced and reproduced by economic and social forces (Oliver, 1990a).[3] The mode of production plays a key role in producing the category disability and in determining societal responses to people with disabilities. In contrast to the medical model that situated disability in the abnormality of individual's physical impairment, the social model of disability 'focuses on the

fact that so-called 'normal' human activities are structured by the general social and economic environment, which is constructed by and in the interests of non-impaired people' (Abberley, 1997:1).

> '... the exclusion and the marginalisation of the disabled is deeply intertwined with the "commodification" of human life; with valuing people for their capacity to produce commodities, services, and profit rather than for diverse talents, abilities and ways of being and becoming. This is one of the more damaging and insidious facets of patriarchal, capitalist societies for it encourages us to reduce human worth to "what we can get out of each other" and in the process helps marginalise those who, for various reasons, can't "compete".'
>
> (Chouinard & Grant, 1995:144-145).

The social model of disability defined the oppression that people with disabilities face as rooted, like racism, sexism, homophobia and ageism, in the economic and social structures of capitalism, in the way work is organised within the capitalist economy itself. This explanation of disability was liberating for many people with disabilities (Crow, 1996), and thus the social model has been 'invaluable as a basis for the critical mobilisation of disability movements as common features of oppression have been recognised across and between different groups of people in different places' (Parr and Butler, 1999:4).

The social model provides a framework, in Western societies[4], from which to begin to: *understand* disability through its base in historical materialism, and to *explain* disability as social oppression, manifested in physical and social barriers in society. For research purposes the social model of disability is used to frame discussion and investigation into how physical and social barriers produce disability in different societies. Where physical barriers, such as steps and kerbs

and heavy doors are spatial manifestations of the design of public and private spaces that have not taken the needs of people with impairments into consideration. Social barriers reflect society's attitudes towards people who are perceived to be different and are thus illustrative of deeply ingrained assumptions about normality and the abnormal body.

> 'Despite everything we can do, or hope to do, to assist each physically disabled person ... to achieve his or her maximum potential in life, our efforts will not succeed until we have found the way to remove the obstacles to this goal directed by human society - the physical barriers we have created in public buildings, housing, transportation, houses of worship, centres of social life and other community facilities - the social barriers we have evolved and accepted against those who vary more than a certain degree from what we have been conditioned to regard as normal. More people are forced into limited lives and made to suffer by these man-made obstacles than by any specific physical or mental disability'.
>
> (UN, 1975:26).

The quotation above by the UN Expert Group on Barrier-Free Design is an insightful and early policy document written in the language of the social model of disability. The regrettable corollary to the comments made in the UN report is that a quarter of a century later local and central governments in the UK are only now beginning to produce policies and practices that are loosely informed by the social model of disability. Consequently previous social policies and their resultant practices in the UK reflect a legacy of the medical model of disability and ableism.

Sociologists ushered in the social model of disability, establishing definitions of disability as relative and not absolute. Geographers have added a spatial dimension to the theorising of disability, recognising that it is spatially

contingent (Gleeson, 1999; Imrie, 1996a). Far 'from being a natural human experience, disability is what may become of impairment as each society produces itself socio-spatially: there is no necessary correspondence between impairment and disability' (Gleeson 1996:391). Geographers established that disability is experienced and produced geographically, and is thus inextricably linked with the production of social space.

Social Space

As a defining and unifying concept within the discipline of geography, space has often led to division rather than unity amongst social geographers. In little over sixty years, Gregory (2000) notes, discussion on the concept of space has moved from conceiving it as *absolute space*, where ontologically objects are fixed at an absolute location, to *relative space*, where ontologically space is always 'under construction by the force-fields established between objects' (Gibson-Graham, 1996, cited in Gregory, 2000:771.). Hartshorne's (1939) text 'The Nature of Geography' guided the course of social geography through the first half of the twentieth century. During this period Cartesian notions conceptualised space as 'absolute' and 'abstract' in that space existed simply as a container for social action, for events and processes (Mitchell, 2000). Hartshorne (1939) nurtured an interest amongst geographers in spatial relations and in so doing he laid the foundations for the development of spatial science and the measuring and mapping of the spatial order of social relations. However, the singular focus on absolute, fixed space, by spatial scientists, was criticised. Olsson (1974) captures

the essence of geographers concerns with spatial science, claiming, 'that the statements of spatial science revealed more about the language its protagonists were talking *in* than the world they were talking *about*' (Olsson, 1974, cited in Gregory, 2000:768).

Critical geographers introduced social theory and political-economy into debates on reconceptualising space, for example, Harvey's (1973, 1982) work on historical geographical materialism. The Marxist geography of Harvey emphasised the importance of constructing a materialist history of space that was capable of grounding concepts of space in specific social formations. Lefebvre (1991) sought to contradict the structural assumption that space was the 'mere territorial projection of social relations' (Martins, 1982:163, cited in Gleeson, 1999:45), proposing instead that society and space were mutually constitutive forces. 'Space is permeated with social relations; it is not only supported by social relations, but it also is producing and produced by social relations' (Lefebvre, 1979:286). From this, Lefebvre asserts that societies produce their own spatialities, just as much as they create observably unique forms of material practice. Indeed, it is through each society's unique social practices that materially-different spaces are produced (Gleeson, 1999). Thus, we 'are confronted not by one social space but by many - indeed, by an unlimited multiplicity or unaccountable set of social spaces which we refer to generically as 'social space' (Lefebvre, 1991:86). Soja (1989) has engaged directly with the work of Lefebvre through his explanation of the 'socio-spatial dialectic' that recognises space as simultaneously 'a social product (or outcome) and a shaping force (or medium) in social life' (Soja, 1989:7). The work of Soja and Lefebvre

on social space provides valuable material for conceptualising and understanding disability as a socio-spatial construct, rather than singularly a social construct (Oliver, 1990a) or singularly a spatial construct (O'Brien, 1991).

Gleeson (1999) draws on the work of historical materialists (Marx and Harvey) and Lefebvre's concept of social space to call for an embodied historical-geographical materialism. Gleeson contends that each society produces its own spaces and social embodiment that are historically and culturally specific understandings of different bodies. The following sections look at how power and discourse produce various and conflicting understandings and experiences of social embodiment through the construction of culturally defined norms.

SOCIO-SPATIAL CONSTRUCTION OF DISABILITY

Disciplinary Power

Over the last decade geographers and other social scientists have drawn heavily on Foucauldian thought to help understand the workings of power and its impact on the treatment of abnormal bodies. Foucault's (1977, 1980) theorising of power refutes traditional concepts of power radiating out and descending from a central sovereign and proposes a form of power administered through the construction of routine and normalisation, which is exercised even in its perceived absence. It is a 'capillary form' of power which 'reaches into the very grain of individuals' and is exercised '*within* the social body, rather than *from above it*' (Foucault, 1980:39).

> 'Power moved from the distant horizon into the very centre of daily life. Its object, previously the goods possessed or produced by the subject, was now the subject himself (sic), his daily life, rhythm, his time, his bodily actions, his mode of life. The power reached now towards the body and the soul of its subjects. It wished to regulate, to legislate, to tell the right from the wrong, the norm from the deviance, the ought from the is. It wanted to impose one ubiquitous pattern of normality and eliminate everything and everybody which the pattern could not fit'.
>
> (Bauman, 1982:40-41, quoted in Clegg, 1989:167).

This process of social embodiment has historically privileged certain biological forms of embodiment as normal and others as abnormal. The surveillance of this process, of identifying the normal from the abnormal, is anonymous (Pringle, 1999) for it operates, according to Foucault (1977), through a capillary form of 'disciplinary power'. It is in *Discipline and Punish* (1977), which is ostensibly a discourse on the French penal system, that Foucault developed his concept of 'disciplinary power' to describe the anonymous, all pervasive power that controlled prisoners. He used Bentham's Panopticon as a metaphor for an effective surveillance mechanism that forced prisoners to internalise disciplinary practices and established norms at all times. The Panopticon was an eighteenth century design of an ideal prison where a central watchtower afforded a view into all the cells, so that at any one time the prisoners could be observed day and night. The fear of constant surveillance was enough to force subjects to internalise routines of self-surveillance and compliance with authority.

The concept of disciplinary power has been extended and applied to populations outwith controlled spaces, in what Hannah (1997) has termed an 'Imperfect Panopticism', to illustrate the ways social practices and discourses penetrate deep

within the body to discipline, control and separate the norm from the abnormal. Foucauldian ideas are useful for illustrating how the power of a hegemonic discourse, as 'capillary power', filters into and influences societies concepts of and attitudes towards disability (Butler & Bowlby, 1997), and crucially constitutes embodied identities (Gleeson, 1993). Thus the normalising society became a conduit for the power of dominant social discourses to be channelled and reproduced spatially and bodily. Foucauldian thinking has been used in this thesis to illustrate the ways that the prevailing discourse of ableism has permeated into the lives of people with disabilities from their everyday social interactions to the design of their homes. The adoption of a Foucauldian approach to power potentially offers new and innovative ways of researching the disempowered. However, one of the weaknesses of Foucault's writing is its failure to extend the debate on power to engage explicitly with empowerment; that is, the realisation of the power each individual has to effect change in their and other people's lives and the ability to exercise that power. Chapter 3 reviews in some detail the burgeoning interest in emancipatory research within the disability literature. Several suggestions are put forward for the failure of emancipatory research to achieve its objectives of empowering people with disabilities.

Drawing on the work of Young (1990a) I want to illustrate how Foucault's disciplinary power is experienced as oppression for certain people in certain spaces.

Oppression

In its traditional usage, oppression means the exercise of tyranny by a ruling group, which carries with it a strong connotation of conquest, colonial domination and sovereign power (Young, 1990a). Apartheid in South Africa is one example of the explicit spatiality of power by a ruling group, the white settlers, over another group, the native and immigrant blacks and Indians. But oppression also refers to systematic constraints on groups that are not necessarily the result of the intentions of a powerful group. Oppression in this sense is exercised and experienced through 'disciplinary power'. The causes of such power are embedded in unquestioned norms, habits and symbols, in the assumptions underlying institutional rules and the collective consequences of following those rules. Getting rid of the rulers or making new laws cannot eliminate this oppression, because the oppression is systematically reproduced in major economic, political or cultural institutions. 'The conscious actions of many individuals daily contribute to maintaining and reproducing oppression, but those people are usually simply doing their jobs or living their lives, and do not understand themselves as agents of oppression' (Young, 1990a: 41- 42). It is not intentional oppression of one group by another, the exercise of such oppression is 'opaque' (Sibley, 1995), it is 'less noticed and so the ways in which control is exercised in society are concealed' (Sibley, 1995: ix). The oppression that is exercised through this form of disciplinary power is, Young (1990a) argues, cultural imperialism.

'Cultural imperialism involves the universalization of a dominant group's experience and culture, and its establishment as the norm. ... Often without

noticing they do so, the dominant groups project their own experience as representative of humanity as ... normality' (Young, 1990a: 59). In so doing the dominant group constructs the differences which some groups exhibit as abnormal in contrast to their normality (Young, 1990a). This process of cultural imperialism, perceived from a dominant culture's perspective, renders oppressed groups invisible at the same time as stereotyping them and marking them out as Other. In contrast, oppressed groups experience of cultural imperialism accentuates their differences from mainstream society making them very visible to themselves, whilst they remain invisible within and to the dominant culture. The following quotation taken from Kimmel (1990, cited in Pile, 1994) portrays the conflicting accounts and interpretations of women and race from the perspective of the oppressed and the unconscious oppressor.

'My own clue that feminist thinking about gender and sexuality had anything to do with me came ten years ago, when ... I sat in on a seminar in feminist theory taught by Donna Haraway. ... In one session, I witnessed a confrontation between a white woman and a black woman. Their argument centred around the question of whether their similarities as women were greater than their racial differences. The white woman asserted that the fact that they were both women bonded them, despite racial differences. They shared a common oppression as women, and were both 'sisters under the skin'. The black woman disagreed.
"When you wake up in the morning and look in a mirror, what do you see?" she asked.
"I see a woman", replied the white woman hopefully.
"That's precisely the problem", replied the black woman. "I see a black woman. For me race is visible every minute of every day, because it is how I am not privileged in this culture. Race is invisible to you which is why our alliance will always feel false and strained to me".
When I heard this, I was startled. For when I looked in the mirror, I thought I saw a "human being", a generic person, universally generalizable. What had been concealed - race, and gender, and class - was suddenly visible. As a middle-class white man, I was able to not think about the ways in which class and race and gender had shaped my

> existence. Marginality is visible, and painfully visceral. Privilege is invisible and painlessly pleasant'.
>
> (Kimmel, 1990: 94, cited in Pile 1994: 265).

The black woman that Kimmel (1990) refers to could quite easily be a disabled woman, or refer to any other social difference that makes individuals conscious of how their body positions them in relation to culturally accepted norms within society. Living in and through a disabled body means that people with disabilities are positioned such that their own embodiment is brought to the fore of everyday living, as a visible reminder of their oppressed, excluded and marginalised status within society. Young (1990a) contends that modern political practice wrongly universalises dominant group perspectives. She calls for attention to be paid to social group differences to correct the invasive and oppressive nature of cultural imperialism (Young, 1990a). Young is referring to social group differences that have previously been hidden and overlooked by social scientists, but are now being uncovered and explored by social and cultural geographers.

People with disabilities are one such group of people that social geographers have until recently largely over looked in their work. However, people with disabilities are not a single generic group, but one composed of many sub-groups including: people with physical, sensory and mental impairments, all of which can manifest themselves as visible and/or (intermittently) invisible impairments. I chose to focus on wheelchair users for this study because, as a group, they are very visible through their use of a wheelchair, and concomitantly they experience both physical and social disabling barriers in their everyday lives. From this sub-

group of people with disabilities I focused on adult wheelchair users aged between 16-64 years. Older people and children were excluded from the study because of the unique health needs, employment status and lifestyles that characterise these age groups, and which mark them out as quite different from those of the adult population. The objective of the study was to investigate the geographies of adult wheelchair users in relation to their housing and in so doing expose the differences and the similarities that exist within this section of the population all of whom live their lives in the shadow of ableism.

In modern Western society the hegemony of an ableist discourse has led to disability being interpreted as abnormal: as placing limitations on an individual's ability to lead a full and 'normal' life, and to perceptions of the disabled as occupying deviant bodies. For the disabled themselves, prevailing social practices have controlled and disciplined their lives and have been responsible for constructing the negative imagery associated with the disabled. As Morris (1994) notes, one of the biggest problems for people with disabilities is that all the undermining messages sent out from society 'become our way of thinking about ourselves and/or our thinking about other disabled people. This is the internalisation of *their* values about *our* lives' (Morris, 1994:103), what Kitchin (2000) refers to as 'internalised ableism'. 'Non-disabled people feel that our difference gives them the right to invade our privacy and make judgements about our lives' (Morris, 1994: 105). For example, people with disabilities are required to self-identify as 'disabled' to be categorised in a community care client group to receive 'special needs' housing (see Clapham and Smith, 1990). Furthermore, the policy of community care and its objective of normalisation: to enable people

to lead as normal a life as possible in the community, is grounded in a discourse which brings to the fore the binary dualism of normal and abnormal. The use of this dualism reflects a discourse of ableism that locates the site of abnormality in the individual's body and not in the dominant social policies and practices.

Normalisation

Normalisation, the project upon which the normal/abnormal dualism rests, offers disabled people the opportunity to be given valued social roles[5] through living lives that are integrated into the community. However, Oliver points out that this occurs in 'an unequal society which values some roles more than others' (Oliver, 1990a:28), and which operates through facilitating for the bodies of the perceived abnormal to converge towards a norm in lifestyle and behaviour that has been defined by socio-spatial factors. Nast (1998) exposes the socio-spatial contingency of dualisms, by demonstrating that norms and the normal/abnormal dualism are not fixed but are time and place specific. She does this by drawing on her experience as a white woman researching black, muslim women in Nigeria, where she was perceived as 'abnormal', as Other, and where she consequently felt 'out of place'. Nast's experience illustrates how social and spatial differences can annul or reverse the hierarchical relationship implicit in a binary dualism. Groce's work (1985, cited in Minow, 1990) further illustrates this point.

Groce (1985) draws on the example of Martha's Vineyard to illustrate how social practices construct the meanings of normal and abnormal. From the seventeenth

to the early twentieth century Martha's Vineyard had an usually high rate of profound hereditary deafness which created a setting where the cultural meaning of deafness was quite different to that elsewhere in the United States. Deaf people were completely integrated into the community of Martha's Vineyard through the pervasive use of sign language. Even people who were not hearing-impaired sometimes communicated with each other in sign language. Groce (1985) says, '[p]erhaps the best description of the status of deaf individuals on the vineyard was given to me by an island woman in her eighties, when I asked about those who were handicapped by deafness when she was a girl. "Oh", she said emphatically, "those people weren't handicapped. They were just deaf"' (Groce, 1985, cited in Minow, 1990:85). The contrast between attitudes towards hearing-impaired people in Martha's Vineyard and attitudes elsewhere demonstrates the socio-spatial contingency of stigma, disability and perceptions of normality. The power relations of the able-bodied/disabled dualism were annulled in Martha's Vineyard, making the dualism redundant, as well as eliminating the social exclusion experienced by the deaf community as a derivative of that dualism. The example illustrates that all dualisms 'whether considered real or not, do not arrive out of nowhere, they are socially constructed from the struggle to maintain ... dissimilarity' (Pile, 1994:263). Hence, dualisms are never neutral they are powerfully hierarchical, in both their social construction and spatial manifestation, reflecting the intersection where social space and social and cultural practices meet to position people as same and Other.

The account of Martha's Vineyard led Minow (1990) to question: Can we invent other practices that deconstruct dichotomous relationships and treat difference as just the variety of human experience, rather than the basis for dividing people into the class of the normal and the class of the abnormal? (Minow, 1990:85). Researchers themselves need to address this question. For there is a danger in the recent interest in geographical research of opening up the margins and listening to the voices of the oppressed, the previously silenced and invisible Others. The danger lies in perpetuating and sustaining the margins, as marginal and oppressed, for the (academic, socio-cultural, economic, and/or political) benefit of the centre. Without the margins there is no centre, for each is defined in relation to the other. Yet there is no permanence in either of these spaces nor a clearly defined boundary delineating one from the other. However, within feminist, postmodernist and now disability literature there is growing interest in identifying ways to 'delimit', to break open the 'space of the same', and recognise the presence of the Other within the space of the same (Gregory, 2000:770). In other words, to recognise the fluid nature, as opposed to the fixed nature, of the boundaries between people and places that characterise the world we live in at the start of a new millennium. Soja (1996) describes this way of thinking as 'third space', of being in a world that values the production of heterogeneous spaces of 'radical openness', and not bounded homogeneous spaces.

This thesis seeks to explore how a discourse of ableism is played out in the construction of physical and social barriers that prevent the production of a heterogeneous, 'third' space. That is barriers that curtail the inclusion of people

with disabilities into mainstream society and the spaces of the same. The construction of *social* and perceived boundaries based on stigma and difference are considered below, but first I turn to the design of the built environment as a *physical* barrier that makes the spaces of the same inaccessible to people with disabilities.

PHYSICAL AND SOCIAL BARRIERS

Monofunctional and Multifunctional Design

The message received by people with disabilities from the built environment is that they do not belong. 'It tells us we aren't wanted in the places that non-disabled people spend their lives - their homes, workplaces and schools' (Morris 1991:26). 'For access', Hannaford (1985:121) argues, 'read Apartheid' (quoted in Morris 1991:27). Imrie (1996a) contends that modernist design created landscapes that were unable to accommodate different bodies, grounded as they were in a discourse that rested and proliferated on the ordering and categorising offered by binary divisions.

Modernism was characterised by what McGlynn and Murrain (1994) have termed the advent of the segregated and mono-functional forms (Imrie, 1996a:80). In this sense, modernism was founded upon the idea of the minimalist building and/or design bereft of (bourgeois) ornamentation or, as Wolfe (1981) comments, 'buildings were to express function and structure and nothing else' (Imrie, 1996a: 81). As the American architect, Louis Sullivan

argued, 'form should follow function' (Imrie, 1996a:81). Sullivan's work was interpreted as the search for universal laws of human habitation and behaviour, of the possibilities of producing 'pure' design, singular styles and forms, which were grafted from the essence of the human being. In this sense, functionality was expressed as a means of maximising building utility, premised upon the idea that human behaviour was wholly predictable and knowable, that human beings conformed to a type, to particular patterns of (able-bodied) normality both in bodily and mental terms. Thus, human beings were, in this conception, reducible to a specific essence, an essence that was the embodiment of ableist thinking, and prevailing understanding of the normal body and normality.

The search for normality was evident in the thinking of Le Corbuiser, one of the leading exponents of modernism. Le Corbuiser believed that the propagation of universal properties in form giving was an essential underpinning of the architect's mission, or, as he commented, 'all men (sic) have the same organism, the same functions ... the same needs' (Le Corbusier, 1927:27, quoted in Imrie, 1996a:81). This search for normality in bodies provided the context from which a distinctly modern movement, or interpretation of 'form follows function' evolved. People became reducible to specific types and thus characteristic of the 'modernist ethic of minimalism, of standardisation' (Imrie, 1996a:86). The embodiment of normality was expressed in a diagram conceived by Le Corbusier in 1925 entitled the Modular, a device that facilitated architects to utilise the proportions of the body to create built spaces (Plate 2.1). Yet the Modular was wholly based on a particular, ableist, gender-specific, conception of a person, an idealised man who was presented as the embodiment of normality.

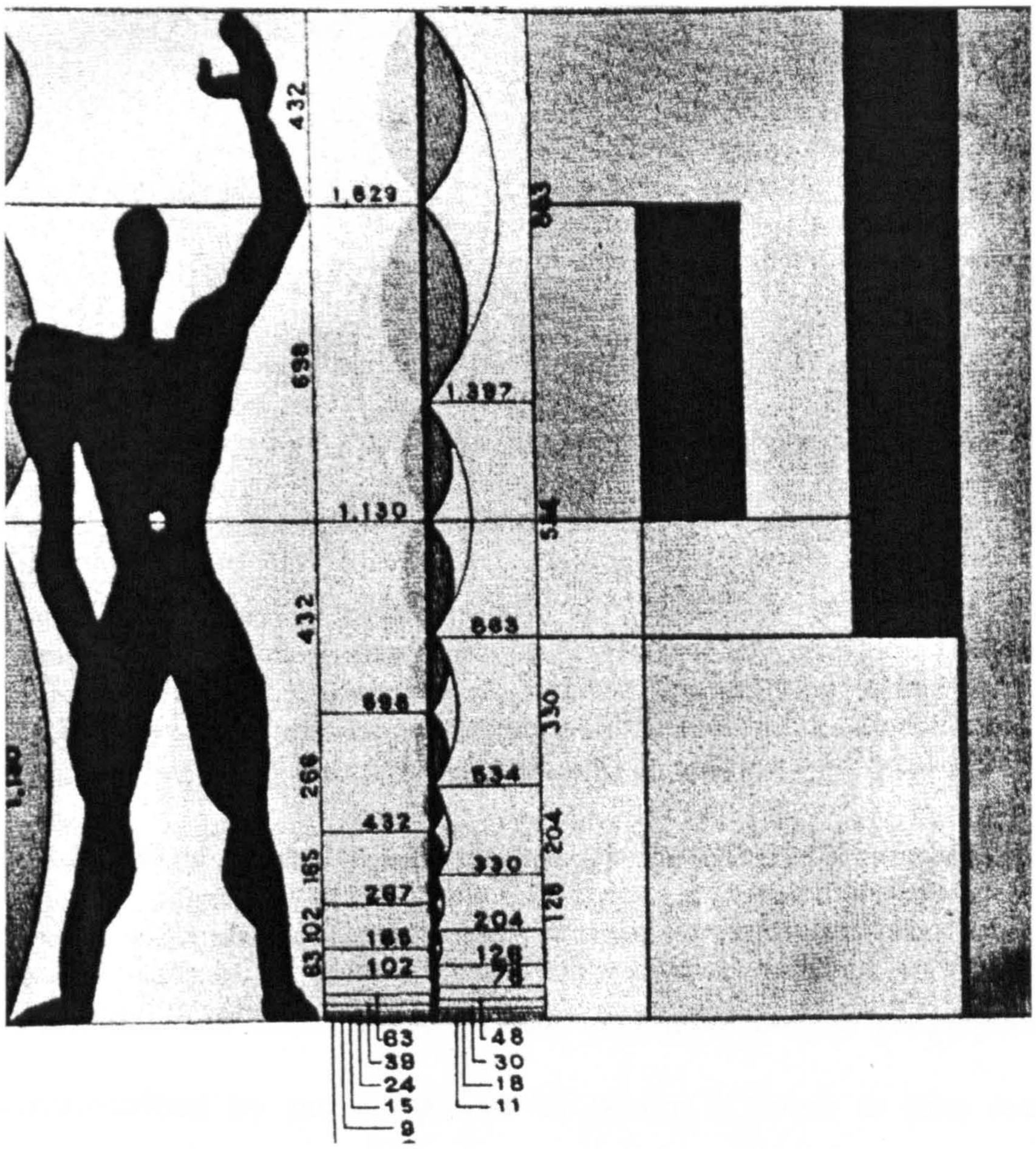


Plate 2.1 Le Corbusier's Modular (Imrie, 1996a:82)

The rationality underpinning the metanarratives of modernist architecture, as Ward (1994) suggests, 'erases differences, standardises experiences, drains the world of colour and texture, and precludes the richness and quality of life', (Ward, 1994:43, cited in Imrie, 1999:28). Lewis (1992) argues that present housing policy is based on a false premise, namely, that all human beings are physically fit, reasonably agile and of 'average' size and height. What architects and planners need to recognise is that most people experience change as a natural

part of the human condition, if not through traumatic injury, illness or disease, then certainly as a direct result of the ageing process.

One of the ironies of the modernist project, noted by O'Neil (1995) is the failure to communicate, or interact, with those who were the (often unsuspecting) recipients of the resultant built forms. As Knox (1987) has commented, how could modernism ever hope to know of the subjective experiences of the users of the built environment when its philosophies more or less discounted the realm of the experiential, personalised, experience?' (quoted in Imrie, 1996a:83).

Grosz (1995) has drawn attention to how women are 'contained' within 'a building which they did not build, which indeed was not even built for them' (Grosz, 1995:56). Women experience spaces differently, as do people with disabilities and other social groups, they have unique geographies that are circumscribed by prevailing axis of power. 'Space is thus ever-mutable, unstable, a function as much of desire and power as of bricks and mortar' (Mitchell, 2000:214). Rose (1996) insists, that no space is free from human intent, human desire and human imagination, and thus space is more complex and less easily described than that which can be plotted on a map or delineated on the ground. '[L]andscapes and places are more than just congeries of material artefacts or empty containers awaiting social action' (Mitchell, 2000:57), they are created by and therefore reflect prevailing power structures and interpretations of embodiment. For people with disabilities the built environment of modernism is synonymous with exclusion and oppression.

'The development of post-modern architecture' Imrie (1996a:75) argues, 'signals the possibilities for a liberating, non oppressive, built environment'. But Imrie also offers a number of caveats and cautions against overly optimistic expectations of the potential scenario of postmodernist developments in architecture. The institutional practices of architecture and building design, he argues, have not opened up to the views and ideas of lay communities as there is no evidence to show that people with disabilities have broken down the ableist structures of the design professions. In addition, he contends that within postmodernist thought, where there is no such thing as a dominant core value, the assertion that society and its architecture are disablist would necessarily be rejected. Thus, whilst ontological changes in architectural design have occurred/are occurring during what is called a postmodernist era, architects are still nestling in epistemologies of modernism and the hierarchical social relations of architectural production remain untransformed. Despite this critique, Imrie (1996a) recognises that postmodernist design along with universal design are the catalysts to ignite the process of unlocking public spaces for people with disabilities.

The permanence of the built form makes the built environment one visible, tangible, and long lasting legacy that symbolises the hegemony of ableist policies and practices. But boundaries to inclusion and exclusion are also experienced as social barriers, as stigma, as feeling 'out of place'. The human landscape can be read at one and the same time as a landscape of exclusion and a landscape of domination (Sibley, 1995). This paradox is expressed through the power of a

dominant culture to monopolize space and keep in place perceived deviant groups in society.

The work of Sibley (1995, 1998) and Madanipour (1998) has contributed to geographical thinking about how and significantly why certain bodies of people are socially and spatially excluded. Central to the process of exclusion is the question of how boundaries become barriers, how boundaries are crossed, and how boundaries can provide security and/or comfort, and generate fear and/or stigma. In essence, geographical interest is beginning to focus on the ways that socio-cultural processes produce boundaries to inclusion and exclusion. However, as Sibley (1995) maintains this is a very much undertheorised concern in human geography (Sibley, 1995), yet central to an understanding of the experiences and practices of social exclusion.

Socially Produced Boundaries to Inclusion

Madanipour (1998) states that boundaries to social exclusion, and thus inclusion, are inevitable phenomena that ensure social order in socially heterogeneous spaces, at a variety of spatial scales, from the home, through the neighbourhood and city to the nation state and the globe. He quotes Aristotle to make his point that urban environments are inherently 'sites of difference'. 'A city is composed of different kinds of men [sic]; similar people cannot bring a city into existence' (Madanipour, 1998:79). Madanipour's argument is that, boundaries to social inclusion/exclusion lie in the complex social interactions between and within different social groups in space, and not in clearly defined class based

distinctions between rich and poor. This is an important distinction that he makes that shifts the focus of attention away from traditional approaches to social inequalities based on economic criteria (ie poverty and the underclass) to addressing issues of social integration and participation from an holistic perspective. Marsh and Mullins (1998) criticise a socio-cultural approach to exclusion, insisting that there is a danger that, once 'the link between income poverty and deprivation is broken then there is a danger that almost all households might be depicted as socially excluded in some way, and the concept becomes of limited analytical use' (Marsh & Mullins, 1998: 753). However, as Edgar *et al.* (2000) argue, 'for all its equivocation and complexity, social exclusion has proved to be more than an ideological tool for rhetorically inclined politicians. ... '[t]he emergence of the term [social exclusion] reflects [a successful] attempt to reconceptualise social disadvantage in the face of major economic and social transformations' (Gore, 1995:3, cited in Edgar *et al.*, 2000:19-20). Others concur, arguing that there is a need to move on from narrowly focusing on income poverty in discussions on social exclusion to reflect the changing reality and complexity of socio-spatial relations (see Fuller, 1998; Philo, 1998; Room, 1999; Samers, 1998). Sibley (1998) suggests that there are other questions like resistance and autonomy, the role of agency and power, which a singular concern with economic structures and labour market integration neglects. This has led to calls to broaden the restrictive view of exclusion centred on poverty and incorporate other processes of exclusion (Lee, 1998), that are consonant with theorising on social space and how each society produces its own social and spatial exclusionary processes.

> 'Most important is the need to recognise the multiple meanings of exclusion. A boundary on the map may represent an insurmountable barrier to some or it may demarcate a space of survival or resistance for others. Thus, in addition to an appreciation of political economy, it is important to be sensitive to the other world views, to know what being on the edge or relegated to the periphery means to those who inhabit marginal spaces'.
>
> (Sibley, 1998: 121).

As a social group, people with disabilities frequently find themselves 'locked in place' by real or perceived barriers that cannot be crossed. Madanipour (1998) is concerned with identifying under which conditions boundaries become barriers to inclusion for certain groups of people. A key idea put forward by Allen et al. (1998) is that 'social cues are encoded in space' (Allen, et al., 1998:). When social cues are interpreted negatively, places and spaces can become associated with negative imagery so that the social cues become literally inscribed onto space creating stigmatised and excluded spaces. The categorisation of particular groups and individuals as non-conforming or abnormal and the resultant siphoning off of these people into certain spaces results in a 'purification of space' (Sibley, 1998:120), where the spaces of the normal and same are kept distinct and separate from the spaces of the abnormal and Other. This process is self-perpetuating for spatial segregation reproduces negative social cues and leads to increasing the social and spatial distance between the same and Other. It reinforces rather than breaks down negative stereotypes and boundaries between same and Other.

Neighbours frequently wish to retain social and physical distance between themselves and stigmatised bodies and do so by creating perceived and imaginary boundaries. At the heart of their reservations is a fear of the unknown,

of perceived non-conformity. The result is all too often a rise in Not In My Back Yard syndrome (NIMBYism): neighbourhood opposition to the close proximity of people and spaces perceived to be non-conforming or abnormal. Wilton (1998) argues that, 'because people internalize social norms as a condition for subjective becoming, their own sense of identity is to some extent dependent upon the maintenance of surrounding social and spatial order' (Wilton, 1998:173). When the dualism between same and Other, normal and abnormal is challenged by physical proximity, the perceived threat to the existing socio-spatial order becomes the catalyst for NIMBYism (Dear et al, 1997, Wilton, 1998). The result is the strengthening of boundaries and differences between 'us' and 'them', 'same' and 'Other', disabled and able-bodied (Wilton, 1998). People (society) and places (spaces) are thus shown to be actively involved in the process of producing and reproducing people (society) and places (spaces) as different. This occurs through the construction of perceived boundaries to inclusion and exclusion (Sibley, 1995, 1998, Wilton, 1998).

This thesis has sought to produce empirical evidence to help understand the processes by which boundaries to inclusion, as described above, are created. The housing of people with disabilities was of interest to me for its dual role in the process of boundary formation. Housing can and does produce both physical and social barriers that can exclude people with disabilities. For example, the physical design of a house is a tangible, visible statement of how accessible a property is to a wheelchair user and thus the presence or absence of physical barriers. However, this study goes beyond such a myopic view of access being curtailed solely by physical barriers, to consider the ways that the imagery of

disabled housing strengthens the differences between normal and abnormal, between same and Other to produce social barriers, in addition to the physical barriers, that lead to social exclusion. An investigation of the different types of housing occupied by people with disabilities has provided a rich source of material to begin exploring these processes of boundary formation that result in the social exclusion or inclusion of people with disabilities within society.

The spatial dimension of social exclusion referred to above, of social boundaries becoming barriers to inclusion and exclusion is not restricted to neighbourhood boundaries in the traditional sense that urban planners, geographers and social scientists have used them to study community and social cohesion. It is a fluid understanding of boundaries that can be real or imagined, tangible or abstract, place-based or non-place based, but is grounded in an individual's innate understanding of their self in relation to others. To help understand this relationship between self/Other and space, geographers have been drawn to the psychoanalytical literature.

Central to the perceptions and feelings people attach to places is the construction of the self, and the way in which individual identities relate to social, cultural and spatial contexts (Sibley, 1995). Geographers have drawn on psychoanalytic theory (Pile, 1996; Rose, 1995; Sibley, 1995) to explicate the inter-relatedness between what Freud found to be the 'connections between the developing self and the material world' (Sibley, 1995:4) and the spatialities of these dynamics (Rose, 2000).

Psychoanalysis is concerned with the fraught processes through which children separate from their initial caregivers (principally their mother) to become, and relate to, relatively autonomous subjects, and with the complicated legacies of that process for their subsequent sense of body, self, other and self-other relations (Rose, 2000:652). Children from an early age become involved in the construction of boundaries as they seek to define themselves. This process is a symbiotic one, dependent on defining the Other in contrast to oneself, just as defining oneself is dependent on the society in which the process takes place. In essence the self is defined by prevailing social and cultural discourses. 'The self is a cultural production' (Sibley, 1995:7). Although the process of differentiating between oneself and others happens from birth, it is an on-going, dynamic and socio-spatial process, as is the process of determining the boundaries of different groups. Thus, what is abject[6] is not fixed, immutable or universal. Social groups enter and leave the catalogue of the abject as negative stereotypes are constructed, deconstructed and reconstructed. The work of Sibley (1995) indicates that there are psychological as well as social and cultural processes at work in the exclusion of marginalised groups. These influences emerge out of a range of historically variable and culturally mediated stereotypes of Others.

PHYSICAL AND SOCIAL EMBODIMENT

The discussion so far in this chapter has highlighted the ways that people with disabilities have been invisible in the design of the built environment, in social policies and a myriad other facets of everyday life. This absence is contrasted with the power of ableist attitudes to produce a clear and visible, but negative,

image of people with disabilities as Other, as abnormal within Western society. Under the weight of ableism and the contradictions embroiled in concepts of visibility and invisibility, negotiating a disabled identity that celebrates one's difference is problematic and can be traumatic. Yet feminist disability scholars are conscious of the need to incorporate the individual differences of people with disabilities into their theorising and research on disability and have been critical of the social model of disability for its silence on differences between people with disabilities and physical embodiment.

The focus of the social model of disability, on identifying spatial and social disabling barriers, has been criticised for overlooking bodily differences (Begum, 1992; Morris, 1991, 1992), and for neglecting to account for how the multiple identities and individual experiences of people with disabilities, based on their physical impairment, gender, age, class, sexuality, and ethnicity, impact on their lives. There is a tendency, Morris (1991) says, within the social model of disability

> 'to deny the experience of our bodies, insisting that our physical differences and restrictions are *entirely* socially created. While environmental barriers and social attitudes are a crucial part of our experience of disability - and do indeed disable us - to suggest that this is all there is to it is to deny the personal experience of physical restrictions ... of illness, of the fear of dying'.
>
> (Morris 1991:10).

Physical embodiment, fatigue and the unpredictability of symptoms (Dyck 1995) all impact on the use of social space by people with disabilities. Sensitivity is therefore called for, to the tensions that exist between recognising 'that much of

our experience of the body is socially constructed and our individual experiences of the physicality of our bodies and their strengths and weaknesses' (Butler & Bowlby 1997:415). The social model of disability, coupled with a geographical imagination, provides a framework through which to explore the ways that socio-cultural definitions of a deviant body configure themselves spatially. Insights from feminism and postmodernism enrich this debate by addressing the tensions that exist between an individual's social embodiment of disability and their physical embodiment of impairment, and how these two interact with disabling barriers in space.

The interplay between social and physical embodiment has been well documented by Dyck (1995, 1996) in her studies of the complex interweaving of space, physical impairment and gender in the everyday lives of women with disabilities. She has delineated the distinction to be drawn between the embodied subject as a social construction, and the body as a physical construction. The former is experienced as relations of power and social control that results from living with a body that is represented by society as deviant and abnormal. In the latter case, the scale of investigation is reduced to the level of the individual and the experiences and problems encountered from living in and through a physically impaired body. In other words, disability is experienced as a combination of the physical limitations placed on people with disabilities arising out of their physical impairment, and the social limitations placed on them arising out of hegemonic discourses that define what a deviant body is and what it can do (Moss & Dyck, 1996).

The incorporation of the body into theorising disability retains a strong link with the social model of disability; as Moss and Dyck (1996) insist, how disabling barriers are negotiated is intricately linked to the ways people experience embodiment. However, the reintroduction of the body into the disability discourse is viewed by some as a retrograde step back towards the medical model of disability. Finkelstein (1996) and Shakespeare (1992) argue that it enables opponents of the social construction of disability to situate the problems experienced by people with disabilities in their body. In other words, to relocate oppression in biology and not society. This argument is countered by, amongst others, Butler and Bowlby (1997) and Hall (1999) who believe that the limitations placed on the functioning of the body by impairment have an undeniable role to play in the everyday geographies of people with disabilities as they negotiate social spaces, and should be a concern of disability geographers.

CONCLUSION

Physical impairment is not selective in who it captures under its wing: although older people are more susceptible to deteriorating mobility, children and adults are also vulnerable. Restricted mobility significantly influences the everyday geographies of a large number of people, and during our lives it will undoubtedly affect us all, even if only temporarily at some point. Geographers should be concerned with how they can use their mapping and navigational skills to develop tactile and accessible maps as Golledge (1993) and others are doing. In addition, there is scope for understanding how prevailing power structures of

present and past societies have constructed spaces that are oppressive and exclusionary for people with disabilities.

Space, society and the body have been shown to be inextricably linked in the construction of disability and how social and physical barriers are negotiated. The present literature indicates that disability is experienced as a complex web of restricted mobility coupled with socio-cultural understandings and imagery of difference and normality. These perceptions are internalised and impact on society's attitudes towards and interactions with people with disabilities, and they are assimilated into policies and practices that influence the design of the built environment and the provision of services. Before moving on to discuss how current housing practices in Dundee are enabling or disabling wheelchair users in the city, the next chapter focuses on methodological issues that are commensurate with current theorising on disability and geography.

3

APPROACHING THE STUDY OF DISABILITY

INTRODUCTION

The volume of literature on methodology in the relatively new field of disability studies is indicative of the importance placed on this question in the genesis of the sub-discipline (see Barnes & Mercer, 1997; Stone & Priestly, 1996). Interest in methodological issues is an acknowledgement of the role of research in the production of knowledge, its role as a powerful political tool, and the influence research can exert in perpetuating or resisting oppression (Oliver, 1992; Vernon, 1997). The main texts in this evolutionary process have concentrated on two fundamental issues: first, the identification of a methodology that is compatible with the social model of disability; secondly, the production of research that both highlights the oppression experienced by people with disabilities and engages with it through working to empower this group of people.

Ten years ago it was virtually impossible to find a geographical paper that addressed disability without medicalising the body. Recent years, however, have witnessed a dramatic increase in work that conceives of disability as a social construct. Three common threads can be identified as unifying these studies. First, epistemologically, recent geographical work on disability has recognised people with disabilities as a source of knowledge, and has given a voice to this

previously silenced section of the population through fieldwork and the written text. Secondly, methodologically, disability studies have moved away from a medical/clinical focus to adopt a social model of disability that conceptualises disability as a social construct. A third thread that unifies disability studies is the adoption of a range of research methods that are predominantly qualitative. It can thus be claimed that in recent studies of disability 'data, method and wider theoretical ideas are intimately linked' (Graham, 1999:79).

This chapter is composed of two major sections, the first is entitled researching disability, while the second focuses on the design and execution of the Dundee study. The first section elaborates on the current methodological debate in the disability literature and addresses issues of positionality, situated knowledge and representation. It also identifies the tools used in this study for qualitative data collection and analysis. The second half of the chapter outlines the design of the study, the methods and the practicalities of carrying out the research into the physical and social barriers that wheelchair users experience in relation to their housing.

RESEARCHING DISABILITY

The Influence of Feminist Research

Geographical studies that have adopted a social constructivist approach have been characterised by the use of qualitative methods and a marked shift away from positivist research methods. This applies to research on disability, gender,

race and a range of other inter-group and inter-personal differences that can be seen to have a social dimension. Over the last twenty years feminist researchers, in particular, have contributed significantly to moving the debate on qualitative, non-exploitative research into mainstream thinking. A common objective advocated by feminists, and now disability scholars, is the need for collaborative research that develops a more egalitarian relationship between the researched and researcher. The respective strategies adopted to achieve this aim are, however, markedly different. Feminists have focused on ways of involving the researcher in the research process, whereas disability researchers have sought to involve their research subjects in the research process[7]. This is an important distinction that I want to clarify further, as it has important implications and consequences for the research objectives of disability researchers.

Feminist researchers have sought to narrow the hierarchical relationship between researchers and the researched by writing themselves into the research process. They have done this through recognising first, that the idea of a researcher being detached and neutral in the research relationship is a myth. Secondly, they recognise the importance of the positionality of the researcher and how this influences not only the way the research is conducted and interpreted, but also the research situation, the interaction with the researched and their responses. Thirdly, they recognise that the relationship between subjects and researchers is relational, that is, the subject of research and the researching agent are seen to be interacting in a social, constantly evolving setting. Consequently, all the researcher can hope to achieve is knowledge that is situated in a specific time and place; what Haraway (1991) has termed 'situated knowledge'.

Disability researchers, on the other hand, building on the insights of feminist research, have not only identified the social relations of the research process as oppressive but argue that the research process itself is oppressive in that it mirrors the social relations between 'same' and 'Other' of wider society (Shakespeare, 1996). The response of disability scholars has been to call for researchers to conduct emancipatory research. Essentially the purpose of emancipatory research is not only to describe and interpret social reality, but to radically change it, and to transform it 'with' rather than 'for' oppressed groups (Maguire,1987). Emancipatory research calls for an alternative position regarding knowledge creation in which research subjects are recast as 'knowing subjects' (Gibson-Graham, 1994) and are encouraged to realise the value and power of their situated knowledges.

The work of feminist researchers has successfully shown that gender makes a difference to people's experiences of and the construction of society and space. Feminist research has thus provided a framework for investigating the differences *between* and the differences *within* groups of people. This framework is being used by researchers in the relatively new field of disability research, who have in addition added a further dimension to the study of difference. Oliver first argued in a 1992 paper that disability research, through the use of emancipatory methods, should seek to *make* a difference to the lives of people. This approach to researching difference creates three potential frameworks for studying disability. These are, first, to investigate and illustrate the differences that disability makes in terms of the relations between people

with disabilities and mainstream society, and secondly, the differences between people with disabilities. Thirdly, to seek, through the process of changing situated knowledges, to 'make a difference' to the lives of people with disabilities. The first two approaches to studying difference involve the process of research as 'investigation', whereas the latter approach is a process of research 'production'. Oliver (1999) distinguishes between the processes of 'investigation' and 'production', using the former to refer to a traditional research process that *investigates new knowledge*, with the latter that explicitly aims to produce the empowerment of research subjects and contribute to *changing knowledges.*

Interest has grown in the potential of research as 'production', as a means to address concerns expressed in the disability literature with 'academic tourists' (Barnes and Mercer, 1997): researchers who use their privileged position to research people with disabilities for their own professional gain without giving anything back or changing the material conditions of the underprivileged. At the same time there is growing recognition of the problems of conducting emancipatory research (Oliver, 1999) and, in particular, the limited potential for research to annul the hierarchical relationship between the researched and researcher (McDowell, 1992; Shakespeare, 1996). Several issues have been raised in the literature with regard to the practicalities of conducting successful emancipatory research, they include that it is invariably more expensive, takes far longer to execute, and is less likely to produce politically acceptable or predictable results (Barnes, 1992). Furthermore, emancipatory research does not sit comfortably in academic institutions where success is measured in terms of

papers published (Kesby, 2000), or where, with regard to postgraduate research, academic criteria regulate both the time to complete a research project and dictate the requirement for single authorship of a thesis. As Shaw has observed, '..my need to ensure that academic criteria were met in order to fulfil the requirements of a MA thesis meant that final control of the project remained with me for the duration of the project' (1995:96).

In summary, theoretical developments within feminist and disability studies have opened up new ways of thinking about disability and new and multiple ways of researching disability. These include research that seeks to investigate critically the social lives of an understudied group of people and to understand the power relations that enable and disable different sections of the society that we all live in. Feminist and disability researchers have, however, placed different emphasises on their approaches to researching marginal groups. It is mainly the feminist literature that has guided this interpretative study, in other words, I retained ultimate control over the direction of the study: the data collection, analysis and interpretation. However, as discussed below, the power relations between interviewer and interviewee were not fixed, but were fluid and constantly shifting between the researcher and researched, between the collector of new knowledge and those that were recognised as possessing that knowledge.

I now want to turn to consider some of the issues I addressed in drawing up a research design for this thesis. In conducting an interpretative study of the barriers encountered by people with disabilities in their everyday geographies, I have attempted to generate 'disabilist versions of objectivity', that is an account

which embraces the qualities that characterise Haraway's 'feminist versions of objectivity'; qualities which Haraway identifies as: 'limited and situated knowledges which are explicit about their positioning, sensitive to the structures of power that construct these multiple positions and committed to making visible the claims of the less powerful' (Haraway,1991:190, cited in McDowell, 1992:413).

METHODOLOGY

Theoretically Informed Research

All research is inherently theory-driven, even though this is not always made explicit (Oliver, 1990a). Disability theorists have recognised that an inappropriate methodology can be oppressive to certain groups of people in certain types of research. For example, in 'A Life Apart', Miller and Gwynne (1972) studied the life of 'incarcerated' (Oliver, 1999) disabled residents at Le Court Cheshire Home. Hunt (1981), who was himself a resident at the Cheshire Home at the time of Miller and Gwynne's study, is vitriolic in his condemnation of the researchers detachment from the disabled residents and their failure to question or challenge the oppressive regime of the home (Stone & Priestly, 1996).

> 'It was clear that Miller and Gwynne were definitely not on our side. They were not really on the side of the staff either. They were, in fact, basically on their own side, that is the side of supposedly 'detached', 'balanced', 'unbiased' social scientists, concerned above all with presenting themselves to the powers that be as indispensable in training 'practitioners' to manage the problem of disabled people in institutions. Thus the fundamental relationship between them and the residents was that of exploiters and exploited'. (Hunt, 1981:5)

The essence of the criticism of Miller and Gwynne's research is not rooted in the qualitative nature of the study but the methodology that guided the data collection, analysis and interpretation. The study illustrates that the choice of theory that informs research is inherently a political decision and never a neutral one (Stone and Priestly, 1996). Disability theorists have thus called for the theory underpinning studies of disability to be overt, for research to be framed within the social model of disability that construes disability as a form of social oppression.

This study has been theoretically contextualised by the assumption that disability is socially created and has sought to investigate how disability impacts on people's lives. However, as work progressed on the thesis I became conscious of the possibility, and probability, of producing a very negative account of the geographies of people with disabilities, and the social and spatial disabling barriers they encountered. Conceptually I could reassure myself that I was working within the social model of disability and adhering to my objectives of seeking ways of identifying and understanding the barriers faced by people with disabilities in relation to their housing. But these were 'real' people I was interviewing, with their own 'different' lives, their own 'different' experiences, their own 'different' strengths, qualities and achievements, they were men and women with complex, multi-layered identities. They were not simply 'disabled people' as opposed to 'non-disabled people'. By restricting my research to the boundaries of the social model I felt I could not account for the varied lives many of the interviewees were leading.

The social model of disability has been criticised for homogenising a naturally heterogeneous body of people and for leaving no space for their bodily differences, for their corporeality (Butler and Bowlby, 1997; Parr, 1998). As noted in the previous chapter, over the last decade the body has received significant attention, and calls for studying the 'geography closest in' (Rich, 1986:212) has filtered into the work of a number of disability geographers. For example, Butler and Bowlby (1997) and Parr (1997, 1998) have drawn on insights from postmodernism and feminist studies in their research on the politics of identity, subjective embodiment and issues surrounding the spatiality of physical impairment. These studies have incorporated notions of corporeality whilst being framed by the social model of disability. The reintroduction of the body into theorising disability resonated through my inductive analysis reassuring me that my inclinations about the need to stretch the boundaries of the social model to incorporate the corporeality and the multiple identities of the interviewees were consonant with conceptual developments in the wider study of disability. The incorporation of differences in embodiment between people with disabilities added a new dimension to the study. No longer was I focusing solely on the difference disability makes to people's lives, but was also picking up the differences between the individuals with disabilities.

Positionality

The theoretical framework that guides research is the principal factor that influences data collection, analysis and interpretation, but the positionality of the researcher should not be overlooked in this process. The growing interest in

positionality in geographical research reflects the impact of feminist and postmodernist approaches. It has led to the recognition that there is no clear window into the inner life of an individual; that the researcher's gaze is always filtered through the lens of language, gender, social class, race and ethnicity (Denzin & Lincoln, 1994:12)[8]. The positionality of the researcher (his/her identity, life experiences and perceptions) is pivotal (Stacey 1988). This recognition has led to persistent calls in the disability and feminist literature for researchers to 'surrender their objectivity' (Stone and Priestly, 1996); to recognise their positionality through acknowledging its power in the research process.

Recognising that the positionality of the researcher can impact on the research process and therefore that he/she cannot be neutral when studying social phenomena is an important step in the development of social science research. But there are two caveats that need to accompany the use of positionality in the research process. First, by focusing on the fluidity of identities and positionalities, concerns are raised of ever revealing the 'truth', as opposed to a discourse of situated knowledge. Secondly, caution needs to be exercised in over-emphasising a researcher's role in the research to the extent of casting a shadow over the researched subjects and how they are represented. These two issues are addressed below.

Situated Knowledge

Social science research has traditionally placed the researcher as the fountain of knowledge, the expert and 'knower', a role which implicitly maintains that the knowledge and experience of Others doesn't count (Stone & Priestly, 1996). Feminism and postmodernism, and latterly the disability literature, have

challenged this role through creating a space for different knowledges to be heard, articulated and recognised. The voices of the Other are seen as offering a valuable contribution to understanding society and space and the functioning of power structures. But this knowledge, like that of the researchers, is seen to be situated, it is dependent on socio-spatial and temporal factors. As Chouinard and Grant (1995) argue, critical qualitative research can no longer overlook the social construction of experience and knowledge, for all knowledge is embodied, that is, it is influenced by our corporeality, and it is situated socio-spatially (Haraway, 1988, 1991).

In a joint paper on disability and sexuality Chouinard and Grant (1995) make the following observation, '[i]t is impossible to ignore the fact that human experience is gendered .... to discuss the "working class" is to ignore (amongst other things) the all important differences between what it is to be the 'woman on the street' as opposed to the "man on the street"' (Chouinard and Grant, 1995:148). The basic premise of this quotation could have referred to people with disabilities (a topic also addressed in the paper) the 'woman' and the 'man on the street' could quite easily be replaced with the 'able-bodied' and the 'disabled person on the street'. The body is crucial in delineating our geographies and how we negotiate spaces and places, and thus our situated knowledges. Feminists refer to 'standpoint theory' to encapsulate the epistemological developments that privilege women's knowledge and recognise the gendered construction of that knowledge. Concomitant with standpoint theory are questions about representation, about bodily differences between

researchers and the researched, and the former's ability to accurately represent other people.

Representation

Winchester (1999) contends that the validity of interviews is not based upon issues of representativeness, but on their potential to clarify causal mechanisms underlying observable phenomena. Although few qualitative researchers would disagree with Winchester's latter point, many would disagree with her disregard for the importance of representation in qualitative interviewing. The politics of representation reflect a concern with the considerable power researchers possess to dictate the course of research and how research subjects are represented. Feminist researchers have found interpretative methods useful in putting 'everyday experience' of the world, as seen by individuals, at the centre of geographical enquiry (Robinson, 1998:420), in Seamon's (1979) words, 'the geography of the lifeworld'. For example, Dyck (1995, 1996) has used in-depth interviewing to explore women's experiences of living with a physically impaired body in disabling spaces. However, it is the researcher, in interpretative studies, who determines which experiences communicate the study's message most clearly. That is because interpretative research relies on the researcher's interpretation of the account presented to him/her, it is in essence an interpretation of an interpretation (Robinson 1998:421), or a 'double hermeneutic' (Giddens, 1984; see Simonsen, 1996:497). Thus whilst interpretative research offers 'thick description' (Geertz 1973) of a research topic, this description is not unproblematic.

Questions of representation also reflect and are limited by a researcher's positionality. 'Th[e] combination of privilege and partiality means that researchers have the capacity to appropriate and misrepresent people's lived experiences' (Wilton, 1999:255). In the quotation below, in the context of research with American women of colour, bell hooks expresses the exploitation that the researched experience when they are represented as research informants. She raises important ethical questions about the relationship between the researched and the researcher, and the researcher and the researched.

> 'It is not just important what we speak about, but how and why we speak. ... Often this speech about the "Other" annihilates, erases: 'no need to hear your voice when I can talk about you better than you can speak about yourself. No need to hear your voice. Only tell me about your pain. I want to know your story. And then I will tell it back to you in such a way that it has become mine, my own. Re-writing you, I write myself anew. I am still author, authority. I am still the coloniser, the speak subject, and you are now at the center of my talk.'
>
> (hooks, 1990:151-152)

In this quotation, hooks highlights the powerlessness of research subjects during an interview, and illustrates that whilst the relationship between researcher and researched is more intense and personal in qualitative than in quantitative work, it remains as ephemeral and hierarchical. Interpretative research using qualitative methods can be just as alienating for the researched, as quantitative research, because 'what might be called the social relations of research production haven't changed one iota' (Oliver, 1992:106). That is, the power relations remain unevenly balanced in favour of the researcher. This relationship is perceived to be all the more powerful and all the more oppressive when researchers from the centre investigate and then represent the lives of people on the margins. The

social relations of this spatial relationship are manifest in the hierarchical relationship that is established between a researcher situated in the centre, colonising the experiences (Oliver, 1999) of the researched, situated in the margins. The researcher is then free to cross back into the centre to analysis, interpret and represent the experiences of people who are now geographically and socially distant from the research process. This process, Oliver (1999) insists, colonises the experiences of people with disabilities but produces little, if any, material change in their lives.

This is a dilemma that Oliver finds difficult to resolve, whilst Shakespeare (1996) and other disability scholars recognise it is a fact that they have to work with. Harding (1991) argues that 'knowledge is situated and scientific methods bind the knower and the known in social relationships of domination and subordination typical of the race-, class-, and gender-stratified society in which science is produced' (cited in McDowell, 1992:408-409). Thus, as McDowell (1992) says, we are forced to recognise that knowledge is always situated, that, 'enunciation comes from somewhere' (Hall, 1991:36). Knowledge cannot be unplaced, it cannot be unpositioned, it is always positioned in a discourse'. McDowell understands this to mean 'that we must recognise and take account of our position, as well as that of our research participants, and *write this into our research practice* rather than continue to hanker after some idealised equality between us' (emphasis in original, McDowell, 1992:409). I also understand it to mean that researcher and researched must recognise their own individual positionalities, making the debate on, for example, whether men can represent women in feminist research or the non-disabled can represent the disabled in

disability research redundant. As Barnes (1992) explains, 'I am not convinced that it is necessary to have an impairment to produce good qualitative research .... Analytically, the experience of impairment is not a unitary one. The range of physical, sensory and intellectual abilities within the disabled community is vast. .... Having an impairment does not automatically give someone an affinity with disabled people, nor an inclination to do disability research' (Barnes, 1992:121). The positionality of the researcher during fieldwork is further elaborated on below (see Execution of Study).

Feminist research has contributed significantly to interpretative research. First, it has done much to recognise the complexities of the relationship between the researched and researcher. Secondly, it has contributed to the understanding that all knowledge is necessarily situated and can only reveal a partial understanding of the world under study. These findings I believe make a valuable contribution to social science research and are an honest account of the process of knowledge production that all researchers are involved in. They raise issues that I was sensitive to when conducting this interpretative study.

METHODS

Qualitative approaches are concerned with meaning and interpretation (Barnes 1992) derived through studying the everyday interactions of social phenomena. They are widely used by geographers for small-scale, local studies, where findings are relevant and unique to the researched, and investigation can centre on how the 'power of geography' (Wolch and Dear, 1989) shapes individual

experiences. Theorising disability as a social construct provides a framework for investigation which conceives of disability as embedded socio-spatially and temporally (Gleeson, 1999); that is, it cannot be studied abstractly, separated from the social world that produces it (Oliver, 1992). Qualitative methods have been used extensively in research involving social theorising of health and disability geography (Wilton, 1999), and are employed here to critically investigate both the societal processes by which disability is constructed and the experiences of living in a body whose access to public spaces is delineated by the spatial manifestations of prevailing power structures.

There are a variety of qualitative methods employed in research which is framed by a social constructivist perspective; these include covert or overt participant observation (Eyles, 1988), focus groups (Goss, 1996), participatory diagramming (Kesby, 2000), archival work, and most commonly interviewing (Kitchin and Tate, 2000). Interview techniques range from being loosely structured by the subject matter of the research project to being very structured around a questionnaire that consists of closed questions. Unstructured interviews provide intensive, textual data and allow interviewees to speak for themselves at length on topics relevant to their lives. This contrasts with interviewees being confined by a structured questionnaire that yields extensive data but little depth. Semi-structured interviews utilise a mixture of dialogue (interviewees elaborating on questions relevant to their lives) and structure (a questionnaire) to guide the interviewer through the interview and ensure a specific range of questions are answered. The use of a questionnaire in semi-structured interviews can be reassuring for some interviewees, providing a visible outline of the interview

they are engaged in. For interviewers, a questionnaire can function as an interview schedule/an aide memoire to ensure all relevant topics are covered during the interview. Additionally, the data collected from a semi-structured interview provides quantifiable answers to the key questions that framed the interview. I employed a semi-structured interviewing format for this study.

As the discussion so far in this chapter illustrates there is considerable interest in the epistemological underpinnings guiding qualitative research. But as Hughes and Howcroft (1999) indicate there is 'a noticeable absence of practical guidance' (1999:1), particularly with regard to methods and techniques for analysing unstructured, qualitative data. The growing interest in the use of computers for analysing qualitative, non-numerical data is beginning to address this imbalance (Richards and Richards, 1991a).

The entry of qualitative software into social science research has occurred in two stages. First, there are programmes that operate as efficient clerks, by reducing the bulk of large text records to easily accessed online files (ie ETHNOGRAPH). Gerson (1984) has characterised the computer as a tireless, endlessly efficient clerk who never forgets, while Fielding and Lee (1993) comment that a computer will do anything which is possible on paper but more easily and more efficiently. Faced with a large and unstructured body of field material, computers provide a speedy means of recording data in a written form and permit it to be retrieved very rapidly.

Secondly, there are programmes like NUD*IST (Non-Numerical Unstructured Data Indexing, Searching and Theorising), which I used for this study, that incorporate all the features of the 'efficient clerk', and, in addition, facilitate the recursive process of moving between raw data and coding, a process that characterises 'grounded theory'. The rationale for theory that was 'grounded' in social settings was provided by Glaser and Strauss in their 1967 book, 'The Discovery of Grounded Theory'. Grounded theory is that which is generated and developed through the inductive analysis of data collected during the research process, and contrasts with theory construction through more traditional deductive methods. Hughes and Howcroft (1999) make an important distinction between grounded theory as a methodology that generates theory, and as a method for data analysis, a template, so to speak, which provides a pragmatic tool for analysing qualitative data. The use of grounded theory as a method enables the researcher to learn from and reflect upon the process and the topic under investigation. The thinking/analytical process of grounded theory, Hughes and Howcroft (1999) insist, occurs as an internal process for the researcher, as a cyclical process (Bailey, et al., 1999) of continually moving between raw data and codes that incorporates both creativity and innovation.

NUD*IST is designed to facilitate the use of grounded theory as a method for analysing unstructured, non-numerical data, and the potential to extend this process to build and generate theory. Early manual methods and the first range of software programmes for coding qualitative data 'were often onerous, unreliable and most importantly, an analytical dead end' (QSR Insight, 2000:1). The development of programmes such as NUD*IST enabled researchers to focus

on the analysis of their data, to delve deeper by asking questions of both their raw data and their coding to refine ideas. Not only is the quality of analysis enhanced by the use of computers (Conrad and Reinharz, 1984) but, as Tesch (1990) notes, the use of computers in qualitative research produces real savings in terms of the amount of time needed to carry out a qualitative study. The ability to handle large quantities of data with relative ease means that researchers are no longer tempted to disregard new data because its incorporation would necessitate a lengthy and time-consuming process of recoding. In essence NUD*IST allows researchers greater time to focus on detailed analysis, rather than focusing on the mechanics of coding.

However, crucial questions have been raised with regard to the analysis of qualitative data by the introduction of computers. Kelle (1997), for example, claims that the software programmes can be used for no more than 'data administration and archiving' rather than tools for 'data analysis' (Kelle, 1997: para.6.3). Others argue that researchers will become detached and alienated from the in-depth analysis and the attention to fine detail that is required for handling qualitative data (see Kelle and Laurie, 1995; Seidel and Kelle, 1995). Coffey et al. (1996; cited in Kelle, 1997) have expressed their concerns that the increasing use of computer software could lead to researchers adopting 'a new orthodoxy of qualitative analysis' (Kelle, 1997:para.1.1) that would go against current postmodernist trends which foster the acceptance and celebration of diversity, not only in relation to conceptualising research but also in the methods used for research.

Despite these criticisms the use of software programmes have enabled researchers to counter the more general and constant criticism of qualitative research that it is neither scientific nor rigorous and that the analysis and the findings cannot be verified. The method of doing grounded theory research, of moving between raw data and coding in the process of analysis (that NUD*IST mirrors) is of enormous value in that it provides 'an audit trail that illustrates how conclusions were arrived at' (Hughes and Howcroft, 1999:11). In addition, the computer itself, Kelle states, 'represents a strong metaphor for systematicity, objectivity and rigour' (1997: para.1.4), in making the qualitative research process more transparent and rigorous (Conrad and Reinarzm, 1984; Richards and Richards, 1991a). Computer programmes can provide guidance to researchers by encouraging them to document the ways that they arrived at particular conclusions, and to employ systematic procedures in the analysis of data that can be replicated.

EXECUTION OF STUDY

Design of Study

The city of Dundee was chosen as the location for my doctoral research for two principal reasons. First, Dundee has a proven track record of providing special needs housing (Public Health Alliance, 1993), and I was interested in investigating the extent to which this provision met the needs of wheelchair users. Secondly, I had established contact with people from Dundee council's

statutory authorities from a previous study (Doherty, et al., 1995). These connections proved to be useful for establishing initial contact with interviewees and acquainting me with other non-statutory agencies involved in wheelchair support and provision. In conducting this study I used a variety of agencies, statutory and non-statutory, as a bridge between potential interviewees and myself. The agencies used were: the Dundee Limb Fitting Centre (22 interviewees, 44%), Dundee City Council (DCC) housing department (15 interviewees, 30%), DCC social work department (SWD) (8 interviewees, 16%), Margaret Blackwood Housing Association (MBHA) (4 interviewees, 8%), and Dundee ACCESS Group (1 interviewee 2%). Each agency distributed an introductory letter to their clients (Appendix D) thereby ensuring their anonymity in this initial contact phase. The letter outlined the study objectives, topics to be discussed in the interview, and the confidentiality of the information that would be disclosed during an interview. Anyone who was interested in participating in the study was requested to contact me by completing a form (Appendix D) and returning it in an enclosed pre-paid envelope. The response from people interested in participating in the study was relatively high, which is perhaps an indication of the importance attached to housing issues by wheelchair users in Dundee (Table 3.1).

Table. 3.1 Response Rate to Participating in the Study

	No. of Letters Sent	Response Rate	
DCC Housing Dept.	39	21	54%
DCC Social Work Dept.	30	9	30%
Margaret Blackwood HA	17	4	24%
Dundee Limb Fitting Centre	43	24	56%
Dundee Access Group	1	1	100%
Total	129	59[9]	45%

However, the significance of the initial letter that was sent to perspective interviewees, via the agencies, should not be underestimated when considering the response rate or perhaps more importantly why people responded. With hindsight the content of the letter was not neutral, rather it documented the agencies' support for the project and encouraged their clients to participate in the study. Although the agencies received a copy of the summary report (Appendix E) they received no information as to which of their clients were interviewed nor what individual people said to me. This, however, was not made clear in the aforementioned letter, and thus a number of people may have felt under pressure to participate in order to be seen to be doing 'the right thing'. This initial correspondence was not therefore impartial, but rather potentially coercive, reflecting the hierarchical relationship between service providers and service users. The significance of this letter and the way people interpreted it may, in addition, have influenced their conduct and what they said to me during their interview, and how they perceived me and my role: as a neutral outsider or interested insider (my relationship with interviewees is elaborated on below).

The use of multiple agencies was however the key to accessing a group of wheelchair users living in different types, tenures and locations of housing across Dundee. Using a variety of agencies ensured that my sample included people living in unadapted, adapted, purpose built and sheltered housing, and people waiting to move house or for adaptations, that were either owner occupiers or social renters. There was no systematic selection of the number of respondents in each of these categories. Further, there was no control for the socio-economic or demographic characteristics of the people who responded to and eventually

participated in the study. Consequently, there is an uneven distribution within the sample in relation to class, sex, age, household size and house details, with fewer people aged under 24 years or between 35–44 years than in other age categories and fewer people living in unadapted housing than in other house types (Table 3.2). The criteria for selecting interviewees was that of 'availability', the sample of respondents cannot claim to be representative of the wheelchair users of Dundee. However, given the objectives of the study - to produce a detailed insight into the housing experiences of a group of wheelchair users living in different types of housing - the absence of a systematic or representative sample was not seen as particularly problematic. The findings from this study, however, should only be read as representative of the interviewees experiences, further research would be needed to verify the findings with wheelchair users elsewhere.

In total 50 in-depth, semi-structured interviews were conducted with wheelchair users living in different types of housing and tenancies across Dundee. The age of interviewees was restricted to the adult population, aged between 16-64 years, with the largest age group being 55-64 year olds (38%). Regrettably all the interviewees were white, despite the presence of a substantial ethnic population in the city.

Table 3.2 summarises some basic demographic and socio-economic data about the interviewees, with regard to sex, age, household size, house type, tenancy and household income. The largest tenancy group comprised of owner occupiers (42%), followed by interviewees living in local authority housing (38%), and

Housing Association tenants (20%). With regard to house type, there were more interviewees living in mainstream adapted housing (36%) than in any other type of housing, followed by sheltered housing (30%), purpose built wheelchair housing (22%) and mainstream unadapted housing (12%).

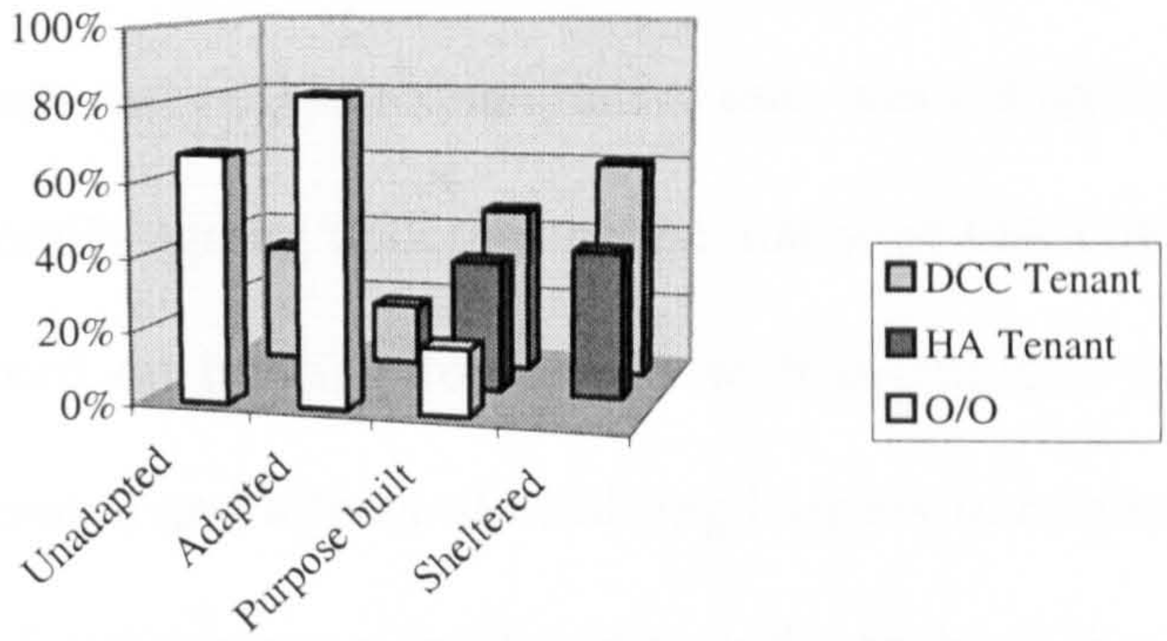
Table 3.2 Socio-demographic Data on Interviewees

		No.	%
Sex	Female	29	58%
	Male	21	42%
	Total	50	100%
Age	18-24 years.	3	6%
	25-34 years.	10	20%
	35-44 years.	5	10%
	45-54 years.	13	26%
	55-64 years.	19	38%
	Total	50	100%
Household Size	Living alone	11	22%
	2 person household	23	46%
	3 person household	11	22%
	4 person household	3	6%
	5/6 person household	2	4%
	Total	50	100%
House Type	Sheltered	15	30%
	Purpose built	11	22%
	Mainstream adapted	18	36%
	Mainstream unadapted	6	12%
	Total	50	100%
Tenancy	Social housing tenant	29	58%
	Owner-occupier	21	42%
	Total	50	100%
Household Income	< £4,999	5	10%
	£5,000 - £9,999	24	48%
	£10,000 - £14,999	12	24%
	£15,000 - £19,999	3	6%
	> £20,000	1	2%
	No reply	5	10%
	Total	50	100%

Figure 3.1 summarises the relationship between tenancy and house type, revealing that owner occupiers were predominantly dwelling in mainstream

adapted housing, and housing association tenants were living in purpose built or sheltered housing. The high incidence of owner occupiers in adapted mainstream housing (83%) reflects their ability to choose to 'stay put' and apply for a home improvement grant from the council to help in the adaptation of their home. With social housing landlords being the principal providers of purpose built and sheltered housing it was not surprising to find that social renters predominated in such housing (Scottish Homes, 1994).

Figure 3.1 Interviewees house type and tenancy



All the names used to refer to interviewees or their family and friends are pseudonyms to protect their true identities. Further background information on the interviewees is provided in Appendix A. These summaries highlight the main characteristics that differentiated the respondents in the analysis of the data, principally: their age, tenancy status, the type of house they were living in and whether they lived alone or with a carer or other family members.

Data Collection

The in-depth interviews were semi-structured around a questionnaire (Appendix C), a format intended to be flexible enough to allow interviewees to expand and

talk at length on a subject. The questionnaire had a dual purpose, it was designed to elicit quantifiable data and to ensure that key topics were covered in all the interviews. It also functioned as an interview schedule enabling me to refocus the interview when/and if discussion became tangential to the subject matter. Thus, whilst the questionnaire provided a framework for the interviews, it also facilitated a dialogue, a conversation with the interviewees that went beyond the confines of the questionnaire itself to gain rich, in-depth qualitative data. These data were used to understand the myriad of threads that contribute to the rich tapestry of wheelchair users' everyday lives in and around their homes. A qualitative approach, rather than a quantitative one, was adhered to as a means of exploring and literally 'going underneath' the statistics that comprise Dundee's notable track record on housing for people with disabilities to look at issues surrounding the causes and affects of disabling barriers in relation to wheelchair users' housing. Furthermore, a qualitative study enabled the interviewees to voice their housing experiences in their own words.

The interviews varied in length from 45 minutes to 2 hours and 30 minutes and took place in the interviewee's home. The interviews were tape-recorded with the interviewee's permission, (only one interviewee requested that the interview not be taped). The majority of interviewees appeared keen to talk, however, I was not always certain as to how the interviewees interpreted my role as a researcher or the true purpose of my visit. For example, on one occasion at the beginning of the interview Simon, the interviewee, interjected and asked if I was interested in the outside of the house and the garden. It transpired that Simon wanted a new garden gate and he wanted to know if I could arrange that for him.

In addition there were interviewees like Liz who could see the potential benefits of the research for people with disabilities generally, rather than for their specific needs:

> *... it's just good to know that there are people who want to help you know, or they want to try to make an impact. I know it's not easy and one person can't do it all, but it's nice to know there are people out there who are prepared to come in and ask questions like that, coz it's the little things that are important at the end of the day. Like if all the little things were taken care of, I'd have more energy to face the bigger things, so you could do what you really want to do instead of struggling to do the little things.*
>
> Liz, interviewed 13/3/97

My overall impression of the balance of power in the relationship between the interviewees and myself was that, it was not fixed, but constantly shifting. Many interviewees were aware that as a wheelchair user they were more knowledgeable about their housing needs and life generally as a disabled person than I was. They knew that they had information that was valuable to me, but in addition there was a sense that interviewees wanted to inform me, as an able-bodied person, to offer me a better insight and understanding of what it meant to be disabled in a society that marginalises the disabled. Thus, although I retained ultimate control over the interview situation and the direction of the questioning, interviewees were empowered through the realisation that what they had to say was important, not only for the research, but in addition, for me as an able-bodied individual. This experience disrupts axiomatic notions of interviewees being powerless in the research relationship, and it raises fundamental questions about the role of researchers in the field and the type of data different people (based on their positionality) can generate from interview situations. Thus, it is likely that a person with a physical impairment conducting interviews with

wheelchair users would experience and develop a relationship with his/her interviewees that was very different from the one I established with my interviewees. This unique relationship would then be reflected in the type and nature of data generated.

Analysis and Interpretation of Data

An inductive approach to the analysis of the data was utilised that allowed for ideas, concepts and themes to emerge out of the data rather than being imposed onto it. To achieve this objective the interviews were transcribed and coded in NUD*IST. Coding progressed over two stages, during the initial, explorative stage I freely allocated codes (free nodes) to interview transcripts as a means of familiarising myself with the data, categorising it and as way of identifying emergent key themes. This process was refined and formalised through transferring the free nodes into an Index Tree. The Index Tree structure in NUD*IST provides for data to be organised in tree like structures of sub-categories (codes) branching off and descending from central, core categories (codes).

At this stage of my analysis I was fortunate to receive private tuition in the use of NUD*IST from Pat Bazeley[10] who advised me that my initial coding strategies were descriptive and not analytical, or as she put it, they were not 'conceptually linked'. Bazeley helped me see how my (novice) coding imposed assumed linkages between codes rather than using NUD*IST to test my subjective inclinations. She argued that I was duplicating coding and in so doing was

presupposing that connections existed between two variables, rather than confirming such connections through the use of the varied index searches available in NUD*IST. Table 3.3 provides an example of the ways that my coding changed based on Bazeley's advice. In Column A a number of categories and sub-categories have been listed and it can be seen that I duplicated the codes 'Positive' and 'Negative'. In Column B there is a central category entitled 'Evaluation', with sub-categories of 'Positive' and 'Negative'. These latter two sub-categories were used for conducting Index Searches, for example Boolean searches using Intersect were used to see when, under what circumstances and who interviewees were referring to when they talked 'positively' or 'negatively' about something. Refining my coding along these lines provided me with a framework from which to question and interrogate the data which the initial coding had not allowed for.

Table 3.3 Coding in NUD*IST

A. Initial Coding of Parent Nodes	B. Final Coding of Parent Nodes
1 Base Data	1 Base Data
2 Physical Barriers	2 House
2 1 House	2 1 Design
2 1 1 Design	2 1 1 Purpose built
2 1 1 1 Purpose built	2 1 2 Sheltered
2 1 1 1 1 Positive	3 Neighbourhood
2 1 1 1 2 Negative	4 Actors
2 1 1 2 Sheltered	5 Evaluation
2 1 1 2 1 Positive	5 1 Positive
2 1 1 2 2 Negative	5 2 Negative
3 Social Barriers	5 3 Mixed
4 Embodiment	6 Feelings
	7 Issues
	8 Activities
	9 Mode of speech

Although the study is primarily qualitative, the data derived from the questionnaire were entered into SPSS, and analysed using descriptive statistics (frequencies and cross tabulations)[11]. These were useful in quantifying different variables and for providing data for visual summaries of the findings presented in tables and charts.

A summary report (Levy, 2000; see Appendix E) of initial findings from the study was sent to all the interviewees and they were offered the opportunity to comment on the report. The aim in sending the report to the interviewees was two fold. First, I wanted them to have some tangible feedback on the study they had made possible through their participation and to enable them to read about the experiences of other wheelchair users. Secondly, I was interested to hear their comments on my interpretation of how they had presented themselves and their disabling living spaces to me. The report was also sent to relevant personnel in Scottish Homes, the Scottish Executive and people working on the ground in the allocation and provision of housing for people with disabilities in Dundee. The report provided a channel for me to communicate and to represent the voices of the interviewees to stakeholders. In addition, it was a medium for raising the profile of the holistic housing needs of wheelchair users and to highlight how present housing practices are contributing to the exclusion and marginalisation of people with disabilities in Dundee.

CONCLUSION

Research can be a powerful political tool and in dealing with a politically sensitive topic like disability, the methodology, epistemology and methods used

all play a critical role in the design of a study and in its outcome. These three factors influence how geographies are represented and whether the status quo is reproduced, critiqued or radically challenged and changed. This chapter has sought to contextualise the framework that I used to conduct this interpretative study of the physical and social barriers encountered by people with disabilities with regard to their housing. I now want to turn to elaborate on the housing experiences of wheelchair users living in Dundee at the end of the twentieth century.

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[1] In a computerised search of 5,000 geographical journals, Chouinard found no references at all to women with disabilities (Chouinard & Grant, 1995). Yet six years after Chouinard carried out this search there are numerous journal articles, books and conference sessions dedicated to work on disability.

[2] The WHO classification of impairment, disability and handicap has served as a framework for behaviouralist geographers to theorise disability, notably Golledge (1993), and thus conceptually work within the medical model of disability. See Butler, (1994, 1996); Gleeson, (1996); Imrie, (1996b) for a critique of Golledge's work.

[3] The only time that people with disabilities have constituted a significant percentage of the work force has been during the two world wars. Humphreys & Gordon (1992, cited in Oliver, 1990a) found that during WWII 430,000 people with disabilities who had previously been excluded from the workforce, were incorporated into factories and into industry, and not just in menial low-grade tasks, but often important supervisory and managerial jobs.

[4] See Stone (1999) for discussion of applying and using the social model of disability for research in non-western countries.

[5] The normalisation project began in the 1960s in Scandinavian social work departments out of concern for the lives of people with learning difficulties. Wolfensberger (1983) working in the US reformulated the term to 'social role valorisation', which sought 'the creation, support and defence of *valued social roles* for people who are at risk of social devaluation' (Wolfensberger, 1983:234).

[6] Abject a term from psychoanalysis, used by Kristeva (1982), it literally means cast out. It is used to capture the importance of maintaining a boundary between the self and Other and defends the boundaries of the embodied self against what are seen as impurities. Sibley (1995) has drawn on Kristeva's use of abject in his discussion of geographies of exclusion to show how the expulsion of 'filth' in both a literal and metaphorical sense is important in constructing spatial boundaries.

[7] I refer here to broad differences for the purposes of clarity. In practice, there is considerable overlap between the approaches adopted by feminist and disability researchers.

[8] Denzin & Lincoln's (1994) omission of people with disabilities is common practice within the geographical and social science literature. The absence of disability from mainstream geographical thinking on issues of difference, silences and marginalises the disabled and thereby reiterates the need to contextualise the experiences of people with disabilities within the literature.

[9] Although 59 people showed interest in participating in the study, a number of factors intervened that reduced the number of interviews that were finally conducted to 50. The other people were unable to be interviewed for a variety of reasons: they could not be contacted to arrange an interview, some were unwell or in hospital, and some were simply not at home at the arranged interview time.

[10] I received valuable private tuition from Pat Bazley, a consultant and trainer in qualitative methods, when she visited St Andrews for a workshop. Pat advised me on using Nudist for the coding and analysis of my data.

[11] The small size of the data set restricted any further statistical analysis of the data.

4

SPECIAL NEEDS HOUSING: ENABLING OR DISABLING?

INTRODUCTION

Housing for people with disabilities has evolved as 'special housing', temporally and spatially different from housing for the 'normal', able-bodied population. Consequently, the housing experiences of people with disabilities are quite different to those of the majority of the population; an experience which reflects a legacy of state involvement and segregation. Through the nineteenth and early twentieth centuries, the 'deserving poor', those who were perceived as unemployable due to physical or mental impairment, were located in workhouses or almshouses and other institutions. These dwellings were socially and spatially separated from mainstream society, a segregation which facilitated the management of perceived problem populations by keeping them out of the everyday view, and thus out of the minds of the able-bodied majority. This period witnessed large numbers of 'aberrant' bodies being siphoned off from normal society into institutions of one form or another. By the late twentieth century, care in the community policies and more recent social inclusion initiatives have emerged, aimed at integrating people with disabilities into mainstream society and ending the spatial segregation associated with previous generations. The 1990 Community Care Act formalised the deinstitutionalisation of people with physical, mental or behavioural differences from institutional and

clinical settings to smaller less medicalised dwellings, ostensibly integrated into mainstream society. Architectural advances in the design of specialised housing accompanied and largely facilitated the growing presence of people with disabilities in the community.

Studies on the housing of people with disabilities have, over the last four decades, charted the impact of different design features on enhancing the independence of this section of the population. Work has focused on design features that can 'enable' people with disabilities by increasing physical mobility and self sufficiency in their living spaces. Few of these studies have been conducted explicitly within the framework of the social model of disability and as a consequence have not investigated how housing is implicated in the social construction of disability, ie how housing can be both disabling as well as enabling. Neither has there been significant interest in the experiences of people with disabilities living in different types of housing or on how housing impacts on people's wider geographies. Through a discussion of house design this chapter will address the issue of 'accessible' housing and 'inaccessible' housing, and the impact different types of housing and tenancy have on enabling or disabling people with disabilities. The chapter begins by charting the development of special needs housing through policy and practice.

DEVELOPMENT OF SPECIAL NEEDS HOUSING POLICY AND PRACTICE

Special needs housing is distinct from mainstream housing in that it has physical or structural adaptations to meet a particular set of needs (see Appendix B for

summary definitions of the different types of special needs housing). The history of special needs housing and social housing are intertwined. From about the mid 1970s the role of social housing changed from that of being principally an instrument of social welfare for tackling socio-economic inequalities, to a scarce resource primarily available to people with a range of specified 'special' social or medical needs. Typically the allocation of social housing is today based on a points system that prioritises housing allocations to people with 'medical' needs. Extra weighting is given to people with a top medical priority, where a medical condition is seen to be exacerbated by inadequate housing.

With the virtual disappearance of local authorities as developers of new council housing, Scottish Homes is now the main provider of capital grants for social housing in Scotland, and the history of its role in this context mirrors, to some extent, the general trend of a movement from universal to specialised provision. Since its inception in the 1930s, as the Scottish Special Housing Association (SSHA), Scottish Homes[1] has performed a variety of roles, providing for general needs housing to accommodate overspill populations from the major cities in the early years to, more recently, acting as an agent of urban renewal in the inner city. The 1980s saw the beginnings of a focus on 'special' housing with the then SSHA beginning to target the needs of older people (in sheltered housing), people with disabilities (in purpose built/adapted housing) and people with learning difficulties (in supported accommodation) (Clapham and Smith, 1990).

As the principal source of funding of new build social housing in Scotland, Scottish Homes plays a pivotal role in influencing the provision of housing for

people with disabilities. Scottish Homes' interest in special needs housing is part of a process that has been evolving incrementally since World War II in the design of housing for people with disabilities. The plight of ex-servicemen and women with disabilities returning after World War II, motivated Sir Francis Tudsberry, the founder of the Thistle Foundation, to act to ensure that they had an alternative future than that offered by a life in an institution. Sir Francis' concept was to build houses that were designed for physically impaired people and their families, enabling them to live independently within an environment where care would be on hand when it was needed. Sir Francis's vision materialised at Craigmillar in Edinburgh in 1944. Here, on a 23 acre site, the Thistle Foundation constructed 103 purpose built houses, a chapel, a residential home for 22 single disabled adults and an administration building containing a range of services, including physiotherapy, hydrotherapy, speech therapy, and craft and nursing departments (Thistle Foundation, 2000). Craigmillar was a prototype for the future development of special needs housing.

A chapter in a 1951 Ministry of Housing Manual, entitled *Housing for Special Purposes,* was one of the first indicators that Government planning was beginning to recognise the housing requirements of people with disabilities. In the chapter attention was drawn to a number of beneficial design features, including; ramps, broad doorways, wide halls, roomy bathrooms, electrical fittings at wheelchair height and strategically located hand grips (Ministry of Local Government & Planning, 1951:16, cited in Borsay, 1980). As Borsay (1980) notes, these design features were an embryonic form of those which would be incorporated later into purpose built housing, but the construction of

such specialised housing at this time was eclipsed by the huge post war demand for housing among the wider – predominantly able bodied - population. It wasn't until a decade later that a scheme, on the initiative of the 'Central Council for the Care of Cripples' and the 'National Federation of Housing Societies', was started to convert a suitable property into a series of self-contained units for wheelchair users (Anderson, 1969:51, quoted in Borsay, 1980). Further developments towards refining purpose built housing for wheelchair users came in a 1963 manual published by the Royal Institute of British Architects, *Designing for the Disabled.* The following year a governmental circular, *Flats for the Disabled* (Ministry of Housing & Local Government, Circular 54/64) pinpointed the potential of ground floor flats as suitable for purpose built housing (Borsay, 1980:18).

A 1969 study by Skinner (1969) captures the nature of the housing conditions of people with disabilities at the beginning of serious government interest in the housing needs of this section of the population. Skinner's study highlights the tenure, type and size of dwellings occupied by people with disabilities in the London Borough of Tower Hamlets. He reveals how grossly inadequate the housing provision was for people with disabilities in the 1960s. Forty per cent of the study sample (including both the private and social sector) had to negotiate at least one, or a possible maximum of four flights of stairs (Table 4.1; Skinner 1969:66).

Skinner's (1969) study was primarily descriptive with little commentary on the results of his study, but what can be gleaned from Table 4.1 is that, other than the

problem with stairs, many of the reasons cited for dissatisfaction by the interviewees were of a general nature rather than explicitly related to 'special' needs. For example, the need for smaller accommodation and the need for a garden are prioritised over difficulties in getting out, being on a lower floor or the need for an indoor toilet. In some ways Skinner provides richer information about general housing conditions in an inner city neighbourhood in the 1960s - the dirt, the noise, the dampness, the lack of sanitary facilities - than he does about the particular housing conditions of people with disabilities. However, these findings also illustrate the socio-spatial and temporal dimensions of house design, housing conditions and society's expectations with regard to the quality of housing. It is unsurprising that the 'special' needs of people with disabilities were not being addressed in the 1960s given the salience of the dreadful, general housing conditions prevailing at the time.

Table 4.1 People with disabilities' dissatisfaction with their housing in Tower Hamlets, London, 1969

Stairs	21%	Dirty atmosphere	3%
Need for bathroom	11%	Location	3%
Dampness	7.5%	Need for an indoor toilet	2.5%
Other complaints	4.5%	Condition of property	2.5%
Need for smaller accommodation	4%	Need for larger accommodation	2%
Need for a garden	3.5%	Need for lower floor flat	1.5%
Difficulty in getting out	3%	Lonely	1%
Problem of noise	3%		

Source: Skinner, 1969

The developments that were beginning to be made in the field of housing for people with disabilities culminated in the 1970 Chronically Sick and Disabled Person's Act (CSDPA), which was extended to Scotland by the Chronically Sick and Disabled Persons (Scotland) Act 1972. The Acts of 1970 and 1972 were

catalysts for changing the housing experiences for people with disabilities. As the Margaret Blackwood Housing Association (MBHA Part II, 1994) has noted, prior to the 1970s the housing needs of people with disabilities were publicly unrecognised. The 1972 Act required local authorities who had duties under the Social Work (Scotland) Act 1968 to 'chronically sick or disabled persons' to make arrangements for the following matters (among others):

- Practical assistance for a disabled person in her or his home.
- Assistance in arranging for the carrying out of works of adaptation in a disabled person's home or the provision of any additional facilities designed to secure greater safety, comfort or convenience (Herd, 1999:34).

The Local Government and Housing Act 1989 moved legislation further in favour of people with disabilities by introducing Home Improvement Grants specifically for adapting houses. The Housing Grants Construction and Regeneration 1996, Section 24 (3) supplemented the 1989 Act by introducing means testing for the allocation of adaptation grants. It also imposed a duty on housing authorities to consult with their social work department on all necessary adaptations. Home Improvement Grants were made available to owner occupiers and private tenants enabling them to incorporate many of the unique features of purpose built wheelchair housing into mainstream houses. Adaptations can range from structural changes to dwellings, such as extensions or the creation of an accessible downstairs shower-room, to less intrusive alterations, such as the installation of a stair lift or ramped access to the front door. Grants are available for alterations to a disabled person's present house, or where he/she is going to live once the alterations have been carried out. The local housing authority can pay up to 75% of the approved cost of the adaptation, with a maximum

allowance of £9,450 (Scottish Homes, 1999a)[2]. However, the allocation of home improvement grants under the Housing (Scotland) Act 1987 is discretionary, and a study by Herd (1999) found that two Scottish councils were spending no public funds on adapting properties in the private sector. As Herd notes, councils adopting a blanket policy of not giving grants, may be guilty of 'fettering their discretion' and could be subject to judicial review' (Herd, 1999:25).

Local authorities who do provide grants for individual adaptations find they dig deep into annual costs; in England £351 million was spent on adaptations in 1994 (JRF, 1997). Herd (1999) reports that 32 councils in Scotland spent at least £13,476,000 on adaptations in a single year on their own housing stock and twelve councils reported spending just under £2 million on adaptations for owner occupied homes during the same time period. Councils appear to prefer tenants to move to a purpose built or adapted house rather than adapting more of their now depleted housing stock. Although such an approach appears to make strategic sense in the context of local authorities' diminished ability to build new social housing, it fails to take into account the social housing needs of disabled tenants and their possible desire to stay put and remain in a familiar neighbourhood where they can predict and negotiate the physical and social barriers they encounter.

In a Department of the Environment circular in 1974 a distinction was made between mobility housing[3] and wheelchair housing. Mobility housing was designed to 'visitability' standards, to enable wheelchair users to visit other people's houses, whereas wheelchair housing was designed to 'livability'

standards, providing wheelchair users with full access throughout the house, including into the kitchen and bath/shower-room. The elimination of stairs and steps, both within the house and in the immediate vicinity of the house; and increased space within the house, beyond Parker Morris standards,[4] became the key features of wheelchair housing (Borsay, 1980). It is estimated that there are 200,000 people in the UK who are permanent wheelchair users and a further 200,000 semi-ambulant people who use a wheelchair on an ad hoc basis (Cope, 1999). The former would be assessed as requiring fully adapted wheelchair housing and the latter would qualify for either wheelchair or mobility housing.

Two studies conducted by the Department of the Environment, one on purpose built housing (Morton, 1976) and the other on adapted housing (Goldsmith & Kirby, 1977) shed light on the housing conditions of people with disabilities at the inception of purpose built and adapted housing. The timing of these two studies, which coincides with government legislation (Chronically Sick and Disabled Persons Act 1970, (Scotland) 1972) giving local authorities the responsibility of providing special housing for this section of the population, is indicative of the government's interest at the time of improving the housing conditions of people with disabilities.

The findings from Morton's (1976) study reveal, somewhat predictably, that a move to a purpose built house offered people with disabilities the possibility of greater independence and enhanced people's satisfaction with their house. Table 4.2 summarises the problems encountered by people from Morton's (1976) study prior to moving to a purpose built house and contrasts them with findings from

Skinner's 1969 study. The final column in the table highlights some of the positive features experienced by interviewees after moving to a purpose built house.

One of the main differences between 1969 and 1976 is that by the later date people with disabilities were prioritising uniquely disabling barriers as the principal obstacles within their home rather than more general housing problems. This reflects a growing awareness of the unique and special housing needs that people with disabilities have and that need to be addressed, in addition to more general housing needs that apply to the whole population. Both the Morton and Skinner studies highlight the important role stairs play in disabling or, in their absence, enabling people with disabilities, and illustrate how conscious and spatially aware people with disabilities are of this particular barrier within their living spaces.

Table 4.2 Disadvantages of Mainstream Dwellings & Advantages of Purpose Built Dwellings, 1969, 1976

Skinner's Study 1969		**Morton's Report 1976**			
Dissatisfaction with Home		**Disadvantages of Former Home**		**Advantages of Purpose-Built Home**	
Stairs	21%	Stairs inside	46%	No stairs inside	28%
Need for bathroom	11%	Steps outside	33%	More space	24%
Dampness	7.5%	Difficulty using bathroom	17%	Able to move about easily	24%
Other complaints	4.5%	Narrow doors	14%	Special fittings	24%
Need for smaller home	4%	Unsuitable for wheelchair	13%	Improved heating	18%
Need for garden	3.5%	Outside WC	12%	Convenient bathroom	15%
Difficulty getting out	3%	Difficulty using WC	8%	Nice views	13%
Problem of noise	3%	Sleep downstairs	8%	Wide doors	12%
Dirty atmosphere	3%	Narrow passages	7%		

Source: Skinner, 1969; Morton DoE (1976, pp.14-15, TT 9 & 11)

These findings are reinforced in Goldsmith and Kirby's (1977) report on adapted housing. Two-thirds of the adapted dwellings studied were of two or more

storeys, and no fewer than 70% of the interviewees living in such properties were 'handicapped'[5] by steps at entrances. One-tenth of those in adapted dwellings had an inaccessible upstairs toilet (the interior space of the toilet was a further disabling factor), and one-fifth an inaccessible bedroom. The general inaccessibility of upstairs rooms in adapted dwellings led to one-third of the interviewees living in a converted living room. Narrow doors and passageways were another major inconvenience, both inside and into the house, reflected in one in ten of those in adapted dwellings never going out (Goldsmith & Kirby, 1977:1241). What is evident in comparing the results on adapted housing (Goldsmith and Kirby) with those on purpose built housing (Morton) is that the latter creates greater opportunities for freedom of movement than does the former. However, improvements are continually being made to narrow the disparity between adapted and purpose built houses and increase the benefits to people with disabilities of 'staying put' and adapting their homes. A study by Dunn (1987, 1990) highlighted how adapted housing can eliminate internal housing barriers and consequently impact on determining disability outcomes. He addressed the role of adaptations on independent living outcomes in a quantitative study framed within the independent living paradigm[6], and found that adaptations were vital in enabling people with disabilities to be more independent and to lead productive lives in the community.

In a British qualitative study on adaptations, interviewees expressed concern about the visual appearance of adaptations, particularly external ones (JRF, 1994). It was found that 'one disabled councillor had succeeded in securing a provision in his authority's community care plan that adaptations should be

aesthetically pleasing and not be a social embarrassment' (JRF, 1994). Furthermore, interviewees were concerned, for reasons of security, that adaptations should not advertise the fact that their home had a disabled occupant (JRF, 1994). The JRF (1994) findings illustrate a further development occurring in the 1990s with regard to identifiable barriers associated with the housing of people with disabilities. As people began to appreciate and benefit from the architectural advances in the physical design of special needs housing, they began to look beyond the bricks and mortar to social disabling barriers. Stigmas and stereotypes that are endemic within a society can become inscribed onto and associated with certain spaces and places. It is evident that at least some of the people interviewed in the JRF study (1994) were conscious of how the built environment can perpetuate culturally defined stigmas and negative imagery. The issue of adaptations is thus problematised by this study (JRF, 1994) drawing attention as it does to the conflictual nature of special needs housing. That is, on the one hand, adapted and purpose built housing can enhance the independence of people with disabilities (Dunn, 1987, 1990; Morton, 1976) while, on the other hand, marking out disabled bodies and spaces as being different. In a society that associates the disabled body with suspicion and perceives it as abnormal, integrated adapted and purpose built housing, by reducing the physical distance between same and Other, challenges established perceived imagery of disability. But this process also creates, especially where adaptations for disability are visible, fertile ground for the erection of social boundaries ensuring social distance is retained between the same and the Other when physical distance has been reduced.

One explanation as to why special needs housing is stigmatised for being different is precisely related to its difference from mainstream housing. Adapted or purpose built housing stands out, it draws attention to itself because there are so few specialised houses in the housing market. For people with disabilities this difference not only leads to the potential of them and their housing being stigmatised, but it is also synonymous with an inadequate supply of suitable housing.

Meeting Demand for Special Needs Housing

The profile of housing types in Scotland, drawn from the 1991 Census, shows that Scotland has an overall high percentage, 40%, of flatted properties. Such a housing environment causes difficulties for people with disabilities both as tenants/owner-occupiers and as neighbours (Disability Scotland, 1994:9). This problem is particularly acute in the social housing sector. A near freeze on local authority new build housing has left housing associations as the principal providers of new build social housing and special needs housing. In addition, the Housing (Scotland) Act 1980, which gave sitting council tenants the Right to Buy their property at a reduced rate, has resulted in a rapid diminution in local authorities 'quality' housing stock. Much of the remaining local authority housing stock is both difficult and costly to adapt because it consists of flats with steps or houses with upstairs bathrooms (Spicker, 1993). In reducing the volume of social housing suitable for adaptation, Right to Buy has penalised people with disabilities (Smith, 1997) and other socially excluded groups who, living at the

margins of society frequently have the greatest housing needs and the greatest difficulty accessing the owner-occupied housing market.

In the 1991 Census a quarter of all households in Scotland reported that at least one person in their household had a 'limiting, long term illness' and that about 100,000 of these households lived in housing which had no accommodation at ground floor level. Although not all of these people would necessarily have a physical impairment, it is likely that many would have mobility problems (Disability Scotland, 1994). The estimates in Table 4.3 suggest that housing need is substantial for people with disabilities, with the proportion of needs met less than a quarter for both wheelchair housing and ambulant housing (Scottish Homes, 1994).

Table 4.3 People with Motor Disabilities: Housing Need and Provision Compared

	Needed	Housing Units No. Available	% Need Met
Wheelchair Housing	9,442	2,011	21
Ambulant Housing	16,756	3,897	23

Scottish Homes 1994, Source: Scottish Office Statistical Bulletin HSG/1992/8

In a survey of local authorities' estimates of their unmet housing need for people with disabilities, 17 of 32 Scottish councils reported shortages of 6,613 houses built to wheelchair accessible standards. A further 12 councils did not quantify their shortages for wheelchair accessible housing (Herd, 1999). The construction of new wheelchair housing is guided by estimated prevalence rates. However, wide variations exist in calculating prevalence rates and consequently in estimating need. Table 4.4 summarises the variable prevalence rates that have

emerged out of studies using different techniques for estimating the requirement for special needs housing. The table illustrates a pronounced variation in the prevalence rates from 26 to 85 per 1,000 disabled people for the age group 16 to 64.

Tale 4.4 Estimates of Prevalence of Disability for those Aged 16-64 Selected from Six Surveys

Study	Rate per 1,000
1988 - OPCS Disability Survey	72.5
1987 - Warren	26
1983 - Hanley & McAndrew	31
1981 - Patrick et al.	85
1978 - Knight & Warren	41
1971 - Harris et al.	37.5

	Rate per 1,000
Mean estimate	47
Min. estimate	26
Max. estimate	85

Scottish Homes, 1994:15

The statistics used to compile Table 4.4 should however be read with caution. Data collection on adapted or purpose built housing for people with disabilities is on the whole ad hoc, haphazard and unreliable, with many housing authorities not recording minor adaptations in the past and keeping poor records even of major adaptations (Disability Scotland, 1994). 'Many authorities unfortunately have little knowledge about which of their properties are accessible or particularly designed or adapted for disabled people. This can make the allocation of housing to disabled people very difficult' (Inside Housing, 1996:5, see also Doherty, et al, 1995; NEQPSGPD, 1995).

In Dundee, the city council has a good track record of providing special needs housing (City of Dundee District Council, 1993; Public Health Alliance, Scotland, 1993), yet there are still insufficient adapted and purpose built

dwellings for people with disabilities in the city. I now want to consider the housing conditions of wheelchair users in Dundee.

HOUSING FOR PEOPLE WITH DISABILITIES IN DUNDEE

Given the restrictions on local authority new build development it was not surprising to find that the tenants of housing associations (now the principal providers of social housing) were living in housing that was architecturally superior, with regard to meeting the needs of wheelchair users, than tenants occupying older local authority and owner occupied properties (Table 4.5). All the interviewees in the study who lived in housing association properties had a ground floor bathroom, an adapted toilet, ground floor bedroom, raised electrical sockets, wide door frames, accessible door handles, accessible light switches, central heating, a parking space and a dropped kerb by their house. When the barriers which made day to day life a struggle in an unsuitable house were eliminated, interviewees experienced increased independence, a less stressful life, and greater energy levels.

> *The house has actually put my life back into perspective, more in control, you know. I can do what I want when I want without any help, without waiting till somebody else is available.*
>
> Liz, interviewed 13/3/97

In contrast to housing association tenants, interviewees who were owner occupiers were living in properties that were less likely to be adapted to meet their personal needs. For example, 42% of owner-occupiers did not have a downstairs bedroom, and 25% did not have a downstairs bath/shower room,

although with regard to general housing needs 92% of owner occupiers had double glazing, compared to only 29% of housing association tenants and 52% of council tenants. Only 4% of interviewees (all of whom were council tenants) did not have central heating[7].

Table 4.5 Design features and adaptations by tenancy

	DCC Tenant	HA Tenant	Owner Occupier	Total
General				
Stairs/steps	11%	/	47%	22%
Level access/ramp to front door	86%	100%	42%	78%
Wide door frames	71%	100%	33%	60%
Raised electrical sockets	81%	100%	42%	68%
Accessible door handles	62%	100%	17%	52%
Accessible light switches	76%	100%	25%	64%
Community alarm/warden	71%	71%	42%	56%
***Open all windows**	5%	14%	17%	10%
***See out of majority of windows**	48%	29%	58%	50%
Double glazing	52%	29%	92%	58%
Central heating	91%	100%	100%	96%
Bathroom				
Ground floor	91%	100%	75%	88%
Level shower[+]	67%	71%	67%	64%
Adapted toilet	52%	100%	33%	54%
Grab rails by toilet	43%	86%	50%	56%
Kitchen				
Lowered work surfaces	62%	86%	33%	52%
Adapted taps	62%	86%	17%	48%
Accessible oven	62%	71%	33%	48%
Bedroom				
Ground floor	91%	100%	58%	82%
Outside				
Parking space beside house	19%	100%	67%	54%
Dropped kerb by house	38%	100%	67%	64%

* bathroom windows were excluded

[+] Although the majority of wheelchair users are likely to find a level access shower most convenient, there are some who prefer and need a bath. Therefore the presence or absence of a level access shower is not truly representative/unrepresentative of an accessible house.

Key:
DCC Dundee City Council Tenants
HA Housing Association Tenants

I have highlighted in Table 4.5 three areas in the design of interviewees' housing that I perceive as requiring immediate attention, they are: stairs/steps, windows and kitchens. I have chosen to focus on these three aspects of house design in detail for the following reasons. Only 22% of all the interviewees encountered

problems with steps and stairs, I felt this issue warrants further investigation since stairs and steps are insurmountable barriers for wheelchair users. The design of kitchens and windows merits further attention because these were the least accessible of all the features listed. Only 10% of interviewees could open the windows in their house, and 50% were unable to see out of all of their windows. In the kitchen, 48% had work surfaces that were too high to be easily used.

The problems associated with stairs, windows and kitchens are discussed below in the context of a broader critique of special needs housing. The sections highlight, first, insensitivity in housing design, secondly, standardisation in the design of special needs housing, and thirdly, the acceptance of inadequate housing by interviewees as an inevitable consequence of living in and through a disabled body.

Insensitive Design

The inconvenience caused by having steps up to a house and an upstairs toilet were by far the greatest problems encountered by interviewees in their home environment. Consequently, the design of interviewees' housing was impacting on their physical and mental health (see Scottish Homes, 1995d). In Skinner's 1969 study 21% of respondents prioritised stairs as the principal problem in their house, over 25 years later stairs remain a disabling barrier for people with disabilities. A 1995 study commissioned by Scottish Homes found stairs alone accounted for 30% of problems noted by respondents (Scottish Homes, 1995c).

In a JRF study (1995) it was found that 54% of people with disabilities could not access their own front door because of steps. In this study, 22% of interviewees encountered barriers to independence in the form of steps or stairs.

When I first met Alex she was living in a two storey flat on the 14th floor of a multi (tower block), she later moved to a purpose built wheelchair house. In her unadapted flat, Alex was unable to go upstairs to the bathroom or her bedroom; movement within her flat was reduced to two accessible rooms, the living room and the kitchen. Neither of these rooms afforded Alex any privacy for sleeping, washing or toileting.

> *Alex: I live in here, I sleep in here, I eat in her, I wash in here. I meet people in here, it's the smallest bedsit in the world. I can get into the kitchen now coz we took the wood from the door, coz I couldn't get in, so I can get into the kitchen and I can turn around.*
> *Susan: What about the bathroom?*
> *Alex: No, the bathroom, that's the bathroom (pointing to the commode beside her bed).*
>
> Alex, interviewed 9/12/96

For Penny the stairs in her mainstream unadapted house and the steps up to her front door make her depressed, exhausted and dependent on her young children for going out and to help her around the house. All of these problems Penny anticipates would be alleviated if she was offered an accessible house that was large enough to accommodate her family (she has four sons living at home).

For those interviewees who had moved into a purpose built house the trauma of having lived with external steps in a previous home was not erased. Liz and Gillian vividly recalled the number of steps that had made them prisoners in their

previous home. Steps that could not be negotiated and hence severely restricted their everyday geographies.

> *Well I was in a ground floor house, but there were like **four** steps out of the door, you went along a path and there was **eight** steps down to the road.*
>
> Gillian, interviewed 12/2/97

> *At the time I wasn't getting out of my mum's house at all and she stayed in a semi and there were stairs outside, **nine**, so like I couldn't get out. My dad is dead, and my mum lives there on her own, and she wasn't able to get me up and down in the wheelchair so I was basically house bound.*
>
> Liz, interviewed 13/3/97

Steps and stairs are the most concrete, visible barrier symbolising physical inaccessibility, consequently they are the physical barrier that urban planners and architects are working hardest to eradicate. Yet able-bodied people are frequently unaware, 'unconscious', of the physical barriers (both steps and other barriers) in their living spaces that disable people with physical impairments. A discourse of ableism has 'blinded' people to the spatial barriers that do not directly affect their lives. For example, it is unlikely that an able-bodied person would be able to recall, like Gillian and Liz, the same level of detail of the steps up to a house they had lived in over two years ago. This state of 'unawareness' or 'unconsciousness' is embedded within an ableist discourse which has undermined the importance of people with disabilities in mainstream society, resulting in their voices and needs being unresponded to, unassimilated and frequently unheard.

The following quotations from Alex epitomise the frustrations of people with disabilities living under the hegemony of an ableist discourse. The first quotation is taken from our initial meeting in her flat in the 'multis', and the second from our subsequent meeting after she had moved to her purpose built flat.

Getting out of here, is mission impossible. I have to get out, well I have to go out with somebody, coz the lift door shuts too quickly. Right, so I've to get out go along the landing, and back into the lift coz I get claustrophobic if I face the wall, back into the lift, the lift door shuts, go down in the lift, come out go through one buzzer door, along to another buzzer door, through the concierge station, and out that buzzer door, then I'm out.

Alex, interviewed 9/12/96

Here I'm constantly having to wheel past the stairs to get out, and I mean it's quite nasty they put my house, so that when I open my front door the first thing I see is a flight of stairs. That annoys me, like I open the front door and think who the hell put a flight of stairs, coz you're looking at it in your wheelchair and thinking why can't I go up there.

Alex, interviewed 11/4/97

Having moved into a purpose built flat Alex no longer has to worry about negotiating steps within her flat or to get in or out. But insensitivity in the design of the new block of flats where she now lives has resulted in a flight of stairs being positioned opposite her front door, as a constant reminder that she is unwelcome and unable to participate fully in 'normal' society. This example is illustrative not only of architectural insensitivity, but stands as concrete evidence of housing providers prioritising the physical needs of access for wheelchair users over and perhaps to the exclusion of consideration of their social and psychological needs.

Interviewees with non-congenital impairments acknowledged that when they first started using a wheelchair they too had prioritised physical access over their need to socialise and lead a full and meaningful life. Coping with the initial shock, redefining a new identity for themselves as a physically impaired person, and negotiating inaccessible spaces inside and outside the home, all coalesced into a perception of physical access as being paramount in the initial days, weeks or months of becoming a wheelchair user. As Ben stressed, he was desperate to find a physically accessible house, and he was willing to accept anything that provided him with the physical access he needed.

> *Well I got this house really quickly, I'd been in hospital for nearly six months and when I came out I was in a friend's house the friend was putting me up. At the time I had the accident I was living with a girl in Arbroath and we'd fallen out then I had the crash. The only person who could look after me was Fred, who's three up. So I'm sitting in the house in the wheelchair, I couldn't go anywhere, I couldn't reach anything, I couldn't do anything, coz obviously his house is for normal people who aren't in wheelchairs, so I was getting really besotted, so I got on the phone. I said, 'I need a house', I said, 'You can't leave me here'. ... They offered me a house, I thought, it's ground floor, it'll do, as long as I'm not three floors up stuck in a house that I can't go anywhere. I couldn't even go out in the fresh air, or even sit at the front door.*
>
> Ben, interviewed 9/1/97

However, housing that at first appears to be accessible and is described as having been built to wheelchair standards, can, when viewed with a critical eye, be seen to have certain features that are simply unsuitable or insensitive to the needs of people with disabilities. Across all tenancies windows are one design feature that appears to rarely meet the needs of wheelchair users, with 90% of interviewees being unable to open all the windows in their house, 50% being unable to see out of their windows and 42% without double glazing (see Table 4.5)[8]. Well designed windows have a dual function, a physical function, being easy to open

and close, and a social function, of enabling people to see out and communicate with friends and neighbours. The results of this study support the findings of Rowles' (1981) that, a suitably designed window enables people to feel a part of their local community especially when they are unable to physically participate in that community. Cope (1999) notes that a recommendation in the Ministry of Housing and Local Government Circular 82/69 calls for housing within sheltered schemes to 'have a lively outlook on to scenes of activity where possible' (Cope, 1999:306). This requires windows to be designed for people to see out of when they sit down and for windows in living spaces to be located with a view of 'scenes of activity'. Marina, Jim and Megan highlight the value of having a window that draws them into the social world outside their house and does not exclude them.

Folks go up and down with the bairns and the pram, coz it's the sea just there. That's the only contact I've got with sitting here, coz I canna go out myself.

Marina, interviewed 20/2/97

It would have been nice to see people. But you see I canna get up the steps and everything, and there's a wee walled garden, which I look at from the living room window, a drying green, a gable end of a house and a load of birds. I would have liked a house on the front of the block (with a view of the road and people passing). I never thought of the front, the front houses weren't nothin' at the time, it's just once you're in the house, you know and you're looking at the terrible view.

Jim, interviewed 27/2/97

You know it's just a small detail and like, but it is very annoying not being able to see out of your windows, especially at the front. What I'm saying is if they were doing other houses like this wouldn't it be nice if you could see out the windows?

Megan, interviewed 28/1/97

One final example of a design feature that epitomises the insensitivity of ableist design in the housing for people with disabilities was found in the kitchen. There was an obvious absence of dining facilities in the majority of interviewees' houses, although this was not raised as a problem by any of the interviewees, probably because many admitted to watching television as they ate. This deficit was often the result of a lack of space for a dining/kitchen table, but it meant that interviewees were eating off trays perched on their knees. However, well-designed kitchens in Margaret Blackwood Housing Association (MBHA) dwellings incorporated a useful low-level breakfast bar/table that divided the kitchen and living room. This feature had a dual function of providing an accessible work surface and space for people to sit together and eat. Unfortunately, the design of similar features in other housing association properties was less successful, as Alex discovered.

> *The breakfast bar, when I saw it I thought that's at the height for a normal breakfast bar, it is too high. Right they said they were going to put in a breakfast bar low enough for me to eat off. Sorry but I don't want to stick my face in the plate, but that is what I'd have to do. It's just too high, but then they just don't think about disabled people.*
>
> Alex, interviewed 11/4/97

Alex's experience draws attention to how architects appear to be working, 'unconsciously', within an ableist discourse. The result being that purpose built dwellings can in theory be fully accessible for wheelchair users, but in practice become unsuitable because of the design of certain features within the house.

Standardised Design

The above section has illustrated that the unique needs of people with disabilities are frequently neglected and overlooked in the design of private spaces, even

when the design objectives are to create an accessible environment. A further problem encountered by interviewees in relation to the design of their homes was the standardisation of features for purpose built wheelchair and adapted housing. The inflexibility in the design of standardised kitchens was found to be problematic for both the disabled and able-bodied.

Wheelchair housing was intended for people who were 'totally dependent on wheelchairs; and for housewives who, although they may not use wheelchairs at all times, use them inside the home and need kitchens which have been designed with this in mind' (Dept. of Envir. Circ. 74/74, para.8, cited in Cope, 1999). Despite a gender bias in the above quotation which assumes that only women 'work' in the kitchen, the message is clear, accessible kitchens are crucial to independent living if an individual wants to/and is able to cook. A kitchen is defined as being accessible when the work surfaces have been lowered to a height that enables someone sitting in a wheelchair to prepare food on the work surface. In addition, leg space is allowed for underneath work surfaces and the sink, and cupboards are lowered to allow maximum access.

However, accessible kitchens are designed to meet the needs of a standardised wheelchair user, that is someone whose body fits snugly around the shape of their wheelchair. They are not designed to be flexible enough to meet the needs of a body that does not conform to a 'normal' wheelchair user. Ben, for example, can not bend his legs, so he is unable to get close to a work-surface that is attached to a wall, even if it has been lowered.

> *The other problem with me with a wheelchair is most, I mean 90% of people in a wheelchair right their legs come across and they come flat down, I can't do that with mine, they don't bend. So when I'm sitting in a*

> *wheelchair I've got an extra 3ft. in front of me, which people don't have. So going under like your sink unit and stuff with your leg outstretched you can't do it, coz I don't bend in the middle, that's all, coz obviously when you bend in the middle you roll on your hips, well if your hips are solid you can't.*
>
> Ben, interviewed 9/1/97

Interviewees' experience of living in a world that standardises the design of buildings and household objects lead to them perceiving material spaces as barriers which engendered a sense that their physical impairment brought about negative consequences. As Gail states, acquiring non-standard products requires people with disabilities to adopt shopping patterns that are different from the norm, and can also be costly and inconvenient for people whose lives are choreographed by inconvenience.

> *I might have actually thought about a kitchen, but you can't go and buy a kitchen, because they're all one height, and they've got that bit at the bottom. So I suppose I'd have to go to a specialised company like everything else. I can't just go to MFI or something to buy a kitchen, because they're the normal height.*
>
> Gail, interviewed 6/2/97

There is an additional problem built into the inflexibility of standardised accessible kitchens that disables able-bodied people. Work surfaces that have been lowered to meet the needs of wheelchair users have the potential to transform an accessible kitchen into an inaccessible or disabling space for an able-bodied person. A 'normal' adult preparing food at a lowered work surface would be forced to work in an uncomfortable, hunched position. The spaces of an accessible kitchen thus have the potential to disrupt the boundaries of the power relations established in the construction of the dualism: able-

bodied/disabled, same/Other. However, the scenario in many households is that an accessible kitchen proves to be unsuitable for both the disabled and able-bodied.

> *Well the problem is the fact that Alan (husband) is very tall, and I'm in my wheelchair, and they adapted it (kitchen), but it isn't really suitable for either of us. It's too low for Alan and it's really too high for me getting in at the sink. And the cupboards are all too high.*
>
> Iris, interviewed 28/1/97

Many interviewees acknowledged that they don't want to cook, they can't cook and that it is dangerous for them to cook. Hence they said they didn't need a fully accessible kitchen which was ultimately a hindrance for their carer, or whoever who was responsible for activities in the kitchen. Goldsmith (1997:343) notes '[r]elevant research and statistical data suggested that some 98% of disabled people in Britain (among them the majority of those who were wheelchair users) could be conveniently accommodated in housing designed to mobility standards[9].' Morag, for example, needs a more accessible house, but stresses that she doesn't want or need an accessible kitchen.

> *They were trying to give us a fully adapted wheelchair house, which isn't what we wanted, because I can't do the things in the kitchen, so we just want a partially adapted house. 'Oh well you've really got to get fully adapted'.*
>
> Morag, interviewed 21/1/97

Housing providers do not appear to be able to accommodate Morag's non-standard needs working as they do within a system that categorises a wheelchair user with needing a fully accessible house. Morag's experience suggests, that in relation to service providers, there is no middle ground, no opportunity for negotiation or flexibility of creating an in-between space, of offering a house that

would meet her needs *and* those of her husband, living as she does in a family unit. Iris and Morag speak for many interviewees who were having problems balancing their needs as wheelchair users with the needs of other people in their household. Both Iris and Morag live in social housing and epitomise the limited choice available to this tenancy group. In contrast, owner occupiers appeared to be redesigning and re-negotiating the spaces of their kitchens to create an environment that suited their family needs, rather than the assumed (standardised) needs of an individual wheelchair user.

John and his wife, for example, decided to have the work surface raised in their kitchen (it had been lowered as part of the design of a purpose built house) so that it would be more convenient for John's wife to do the cooking. Other interviewees concured with John, that it was dangerous for them to cook, they knew they were unable to hold heavy, hot pans, and generally it was felt that it was not essential to have work surfaces lowered that could inconvenience the people who would be doing the cooking. Hence, the kitchen was a room that was infrequently used by many interviewees, even when it was adapted. Although it appeared that the female interviewees retained a strong presence in the kitchen, even when they were unable to physically do anything, they utilised their knowledge of running the house to guide their partners in learning the skills of cooking, cleaning and shopping. Gail highlights the importance of women retaining control in 'their' kitchen, as she joked:

> *I go into the kitchen, instruct Bruce right do this and not to do that. I'm not very good at working, but oh boy am I good gaffer.*
>
> Gail, interviewed 30/1/97

The female interviewees who had become wheelchair users after having been in a marriage for a number of years stated they wanted to maintain a traditional female presence in the kitchen. They felt it was their role and their responsibility to be in the kitchen. It was a role that the women were beginning to realise empowered them within their household and that they wanted to keep. Gail retains a powerful presence in the kitchen through her knowledge of how to cook. Despite, or in spite of, the physical changes to her body the power relations between Gail and her husband are repositioned as her husband accepts his previous absence from domestic duties has left Gail in a powerful position where she can instruct him on running the house. Although a number of the women had in the past been in full time employment they had, like Gail, balanced their working lives with the additional responsibility of cooking and cleaning within the home. The onset of physical impairment and the inability of a wife to continue to carry out all 'her' domestic duties appears to be pushing male partners into the female spaces and roles of the home. This transition and renegotiation of domestic space, including the associated power relations, appears to be challenging and changing established male/female roles within the home, more quickly and more dramatically then the trickle down affect of socio-cultural discourses within wider society.[10]

The bathroom was another room that was contested with regard to the standardisation of features in purpose built or adapted properties. As Jim explains, he wasn't offered a choice of a bath or a shower, because, as a medical priority, showers have become standard features in houses allocated to people with medical needs. Jim's experience points to the problems of standardising

houses, and how his difference is overlooked because he lies outwith the 'normal' needs of people with disabilities. Consequently he feels silenced and powerless to make decisions affecting his individual needs and preferences.

> *Jim: Well I like my bath.*
> *Susan: Did they ask you if you wanted a bath?*
> *Jim: No, no, I asked them.*
> *Susan: What did they say?*
> *Jim: Oh disabled folk dunna get a bath, or somethin' like that.*
> *Susan: How did that make you feel?*
> *Jim: Oh I thought it was terrible. I'm getting used to the shower now. I'd rather lie in a hot bath, coz I take a lot of pain in my back.*
> *Susan: It would be nice to lie down?*
> *Jim: Yeah. Ah, I'm getting used to it.*
>
> Jim, interviewed 27/2/97

The emphasis on sameness, on uniformity, at the heart of modernism, was, Imrie (1996a) argues, problematical for its failure to differentiate between users and to recognise that places and spaces need to be multifunctional to cope with human diversity. 'Any sense in which it [modernist architecture] could relate to differences in body, human behaviour, or access requirements were all but lost in a style that many have referred to as 'non-contextual' architecture, premised on forms which seemed to deny human subjectivity and the differences in bodily experiences and forms' (Imrie, 1996a:80).

Summary

Overall the design of purpose built wheelchair and adapted housing appears to be having a positive impact on the lives of the people 'lucky' enough to be living in an accessible house. With regard to tenancy, housing association tenants appear

to be living in houses that are architecturally superior to those of local authority tenants and owner-occupiers (Table 4.5). For housing association tenants, the system of medical re-housing appears to be impacting positively on their independence and quality of life. Similarly research by Smith *et al.* (1998) has shown that 'medical' re-housing can (for the minority who can achieve it) be an effective health intervention. Smith *et al.* (1998) demonstrate that medical re-housing is often associated with a move into healthier housing, that results in reduced demands on formal care and an improvement in quality of life. Whereas in the private market, where housing outcomes are 'determined according to ability to pay, not according to need' (Easterlow *et al.*, 2000:373) people with disabilities are struggling to maintain the upkeep of their home, maintain mortgage repayments and transform their house into an accessible home (Easterlow *et al.*, 2000). In other words, owner occupation, Easterlow *et al.* (2000) found, did not appear to be a healthy option. People with disabilities and other health problems did not appear to be reaping the ontological benefits of owner occupation that the majority of home owners enjoy. The authors (Easterlow *et al.*, 2000; Smith *et al.*, 1998) concluded that social housing is the healthy solution for people with medical health needs.

The above two sections on the insensitivity and standardisation of design have highlighted how there are several aspects in the design of social housing for people with disabilities that appear problematic. Insensitivity in the location of stairs and in the design of breakfast bars are just two examples that illustrate the way the design of purpose built housing neglects to consider the holistic housing needs of people with disabilities. Whilst not underestimating the progress that

has been made in the design and construction of wheelchair housing, I want to suggest that mistakes are occurring because fundamentally people are guided in their working practices and social lives by the hegemony of an ableist discourse. Housing is conceived and created within a discourse that sees limitations but is blind to the potential opportunities of 'abnormal' bodies. For example, it is highly unlikely that steps were placed opposite Alex's front door as a malicious reminder that she is excluded from entering the space at the top of the steps, or as a metaphor for her exclusion from wider society. The more probable explanation is that 'no-one thought' about the implications of locating the steps where they are. Simply put, it appears that the able-bodied don't see disability in all its spatial and social guises and disguises. Token gestures are made, because the law[11] now requires them to be made, but as interviewees said, disabled public toilets are frequently unsuitable, ramps can lead into buildings whose interior is inaccessible, and as Alex found out, she had more opportunities to socialise with her neighbours when she lived in a tower block, than she does with her new neighbours in a purpose built flat where the majority of her neighbours live upstairs. Hahn (1986) argues that there is a belief that providing accessibility for people with disabilities is simply the extension of privilege or even charity. Hence access matters still tend to be regarded as technical issues or as compensatory measures merely to assist a small and economically insignificant population with special needs (Imrie & Wells, 1993). The power of the discourse of ableism is evident, as illustrated, in the design of housing and urban spaces, but it is also apparent that people with disabilities are internalising this mode of thinking, creating what Kitchin (2000) has termed 'internalised ableism'. Kitchin (2000:34) uses this term to describe a situation where people

with disabilities 'believe, act on and enforce the beliefs of the dominant non-disabled community'. The next section highlights some of the ways that people with disabilities are assimilating the discourse of ableism that is evident in their acceptance of the inaccessibility of spaces and places as their fate.

Accepting Ableist Design

> *I can't visit other people here coz of all the steps into the houses and into the complex, so I don't go up.*
>
> Donald, interviewed 19/2/97

> *When someone invites me to their house the first thing that clicks in my mind is what's the toilet like?*
>
> Helen, interviewed 6/2/97

> *Anna: The way she had to do it, she had to lock her front door, now she had to lock her living room door, coz Martin was there. 'Now don't come out of there coz Anna's in the toilet', I had to reverse in, bring the wheelchair back out again, to close the door.*
> *Robin: Coz there's no room to manoeuvre the chair inside.*
> *Anna: And you had to stand at the front door in case someone should walk in.*
>
> Anna, interviewed 31/1/97

The quotations above are illustrative of some of the physical barriers encountered by people with disabilities in their everyday geographies. Yet despite these restrictions a number of interviewees seemed to accept the inaccessibility of public and private spaces as their fate, as the inevitable consequence of their failure to conform to ableist notions of normality. This process of internalising ableist values appeared to influence how interviewees conceived and negotiated their disabled identity. It was apparent that many interviewees perceived their disability as an individual problem, rooted in their abnormal body, rather than

understanding how social discourses and power structures within mainstream society are disabling them.

In the quotation below Iris widens the discussion on physical access to include issues relating to place and identity, the freedom to be oneself, to have time on one's own and the ability to 'escape' from stressful situations. The relationship between space and identity, as with many addressed in this thesis, is not problematised by able-bodied people, but is something that is taken for granted in the day to day lives of the majority of the population. 'Normal', able-bodied people can easily go out on their own, or with friends and family, go for a drink, a walk or a drive. Many people with disabilities are unable to exercise such control over where they go and what they do, these decisions are made for them by the design of public spaces. For example, shops, restaurants, pubs, cinemas will be chosen not on the quality of service or product but on the physical accessibility of the building, and this is true for many other taken for granted aspects of able-bodied life. The inaccessibility of mainstream housing is another physical barrier that denies people with disabilities the autonomy to visit friends and family. Iris and Morag appear to *accept* these barriers as an inevitable consequence of being a wheelchair user, and they also accept that if they can't get into other people's houses most of their socialising will inevitably have to occur in their home.

Susan: Although your flat is accessible, presumably you can't go upstairs to see neighbours?

Iris: No. I can only get into next doors, coz they don't have a step into their house.

Susan: What about friend's houses?

Iris: Most I can't get into, that means I have all the entertaining to do. It's just one of the things that ***you accept.*** *... My husband sometimes, they all get fed up, but he can just walk out. That's*

> *one thing that I can't do, that's another frustration* (emphasis added).
>
> Iris, interviewed 28/1/97

Susan: You said your son lives close by, are you able to visit him?
Morag: I can't go and visit my son along there, he is up the top flat, he comes here.
Susan: Do you find that steps prevent you from going to many places?
Morag: Yes.
Susan: How does that make you feel?
*Morag: You just have to **accept it*** (emphasis added).

Morag, interviewed 21/1/97

Special needs housing undoubtedly enhances the independence of people with disabilities inside their house, yet the unique spatial and social characteristics of special needs housing is reproducing an ableist discourse that views people with disabilities as different and dependent. In essence, Morris (1993) argues, special needs housing denies people with disabilities the opportunity for independent living. I argue the antithesis, and suggest two alternative interpretations of special needs housing. First, it is not special needs housing that prohibits independent living but, as illustrated by Morag and Iris, it is the inaccessibility of mainstream housing that disables. Secondly, special needs housing is not stigmatised by its physical attributes, but by its social construction through an ableist discourse. Places come to represent the socio-cultural perceptions of groups of people and can represent spaces of exclusion. Thus, it is the inaccessibility of the bulk of the Scottish mainstream housing stock that contributes to the perpetuation of a discourse that stigmatises special needs housing.

An additional problem associated with special needs housing is reflected in a tradition of distinguishing between accessible and inaccessible housing. Such

binary thinking is a relic of modernist architecture and monofunctional design that has failed to cater for a plurality of needs. Designing housing to multifunctional and universal standards is one way to influence the cycle of house design that, for culturally defined abnormal bodies, is discriminatory and restricts access to mainstream housing and thus mainstream society.

UNIVERSAL DESIGN

The concept of universal or inclusive design first emerged in the USA following the introduction of the 1990 Americans with Disabilities Act (Brown, 1999). Driven by civil rights campaigners, the principle of universal design has grown and is now used by many US and increasingly UK designers. The central tenet of universal design is that a product should be able to be used by anyone, there should be no barriers to use. Building to universal design standards requires architects to stop conceptualising and designing buildings that are monofunctional and embrace an approach to design that is multifunctional and accommodating of the differences between people and places. For as Davies and Lifchez (1987) observe, 'accessibility is much more than admittance to a building or a matter of logistics, but is also a quality of socio-psychological experiences which modernist ideas did little to acknowledge' (cited in Imrie, 1996a:91).

Barrier Free Housing

The concept of universal accessibility within the home has been pioneered by Scottish Homes, as Barrier Free Housing, in Scotland, and the Joseph Rowntree

Foundation, as Lifetime Homes, in England. (A summary of the standards of Barrier Free Housing and Lifetime Homes are given in Appendix B). Calum MacDonald, the Scottish Housing Minister has recently stressed the importance of housing design in supporting independent living for all people, irrespective of disability or circumstance. The key to such design he pointed out was barrier free housing. 'People with physical disabilities should be able to stay in their own home and not have to move or carry out costly adaptations. By steering design towards 'barrier free' standards, we are ensuring that more and more new housing will be built with the whole population in mind. ... This ... widens our commitment to meeting people's varying needs and strives to break down barriers not build them' (Scottish Office, 1998a). Scottish Homes have been moving towards implementing barrier free standards since 1989, and in July 1999 these standards became mandatory for all new public sector housing funded by them. National funding bodies in England (Housing Corporation) and Wales (Tai Cymru) have all introduced accessibility standards as a condition for the funding of new build houses.

> Barrier free housing is more convenient for everyone, from people with prams to those coping with the infirmities of old age. It gives people with mobility problems a wider choice of housing, enables them to be an integral part of any community and allows people to 'stay put' when they grow old rather than having to move house. It is also more easily and economically adapted for more particular needs, should this be required.
> (Scottish Homes, 1993a:3)

The revised 'Part M' and 'Part T' of the Building Standards Regulations to make homes more accessible came into force in October 1999 in England and in April 2000 in Scotland, respectively. The basic principles of the amendments to 'Part

T', with regard to domestic dwellings, are; 'visitability' to enable householders to invite people with disabilities into their own homes, to enable householders to cope better with the infirmities of old age and thus be able to remain longer in their own homes. The requirements specify that a disabled person must, unaided, be able to approach the dwelling from a street or car parking space, gain entry and have access to at least one room and a WC. The principal changes to Part T would require the following provision in all new dwellings other than flats and maisonettes on upper storeys not served by a lift:

1) an access suitable for disabled people from a road or driveway to an entrance to the dwelling;
2) an entrance door with a level threshold and appropriate width for use by disabled people;
3) access within the dwelling suitable for disabled people to all apartments on the storey containing the accessible entrance (with certain exceptions);
4) a WC to be located on the accessible storey;
5) accessible entryphone system and light switches in the common areas of blocks of flats and maisonettes.

(Scottish Office, 1998b:47).

Despite opposition from building companies who argued that barrier free is not a marketable concept nor financially viable (Disability Scotland, 1994), there is evidence to suggest that the additional cost of building to barrier free standards would be virtually non-existent if carried out at the time when major refurbishment is undertaken (JRF, 1996; National Woningraad, 1989). The total cost of building to lifetime home standards, according to work by chartered quantity surveyors Walker Richardson, is that the additional costs of incorporating the standards should normally be between 0.5% and 1% of scheme building costs. The most expensive additional cost results from the inclusion of a ground floor toilet if there was no provision for it in the initial specification,

which is common with traditional two bedroom, two storey British houses (JRF, 1997a).

> '... advocates of barrier-free design and architectural accessibility recognised the legal, economic, and social power of a concept that addressed the common needs of people with and without disabilities. As architects began to wrestle with the implementation of standards, it became apparent that segregated accessible features were 'special', more expensive, and usually ugly. It also became apparent that many of the environmental changes needed to accommodate people with disabilities actually benefited everyone. Recognition that many such features could be commonly provided and thus less expensive, unlabeled, attractive, and even marketable, laid the foundation for the universal design movement.'
> (Story, Mueller and Mace, 1998:10).

The anticipated long-term benefits of amendments to Part T are first, that barrier free housing has the potential to offer people with disabilities more choice in the housing market in respect to location, tenure[12] and house type. Secondly, it could engender greater social independence and inclusion by providing physical access to neighbours, friends and family's houses. Thirdly, it could negate the stigma attached to special needs housing, based on the visible differences of such housing from the bulk of the housing stock. Fourthly, it could curtail state sponsored surveillance of the location of and occupants of special needs housing, enabling people with disabilities to 'disappear' in mainstream barrier free housing. Finally, the system of medical re-housing that functions through associating disability with illness and ill-health, (when the two are not synonymous, Herd, 1999) could be phased out of the allocation process. The link between disability and ill-health, Herd (1999) argues, is attributable to housing practitioners working in the discourse of the medical model of disability, the reality of which is manifest in an inadequate supply of accessible housing.

> 'It is because there is a shortage of accessible houses that housing providers require disabled people who do not enjoy equality of housing opportunity to submit to often unnecessary questioning about detailed medical matters. In reality, these tests reveal little about people's housing needs and say much about the limited choices available to them'.
>
> (Herd, 1999:59).

The following quotations illustrate Gail's insistence that houses should be designed to accommodate a divergent range of bodies. Likewise, Ben sees the benefits of barrier free housing based on his experience and perception of spaces designed to accommodate a range of physical abilities. Both Gail and Ben argue that the spatial manifestations of their corporeality would be lessened through the construction of housing to universal design standards that would open up a heterogeneous space to accommodate differences.

Gail: Ey, since I got that built (ground floor bedroom and shower-room), more and more I've felt that all houses should be built like that, because normal able people can use all disabled facilities, but disabled people can't use normal facilities. But I mean I think more and more I've been aware of how difficult it is for me to use something, but how easy it is for Bruce (husband) to use my facilities, you know. If and I mean I don't see why these things shouldn't be considered when new buildings, access and things like that are being built. It's like a lot of disabled facilities, things that are designed for the disabled, more and more is being considered, but it's still a long slow hard struggle. And I don't see why it is such a problem, obviously the first thing is it's expensive. But why it should be more expensive I don't know.

Susan: It's estimated to cost only about 1% more to build all houses to accessible standards.

Gail: Exactly, I think it's inexcusable, we shouldn't have to receive special treatment.

Gail, interviewed 6/2/97

Ben: Oh yeah the majority, I mean in Canada they go over the top for disabled people.

Susan: In what way?

Ben: What they do they design the building, you go in and like there is everything there for normal human beings, you're in a wheelchair with no arms and no legs there is everything there for you too.

They've thought of everything, they think of everything when they design a building.

Ben, interviewed 9/1/97

Smart Homes

Technology has been incorporated into many aspects of our everyday lives, for example, automatic doors into shops, and central locking and electric windows in cars. Yet much of the way we live our lives at home has remained unchanged; advances in home infrastructure have not matched the advances in technological products (JRF, 1999). The concept of smart homes is redressing this imbalance through harnessing some of the technologies that are useful in other settings to improve the quality, independence and security experienced by disabled and older people in their own homes.

Technology was introduced into special needs housing with community alarms in 1977 (Macnaughtan, 1997). The community alarm was perceived by interviewees to be an asset for enabling them to live independently. Although interviewees rarely, if ever, used the service, they saw it as invaluable.

Kevin: ...that's (community alarm) another insurance policy almost.
Susan: Have you ever used it?
Kevin: No but it's always good just to have for insurance.

Kevin, interviewed 2/4/97

The notion of smart homes extends the parameters of how technology can assist people with disabilities to live independently in their own homes (see Scottish Homes, 1999b, Fisk, 1999). This is achieved by the internal environment of

smart homes being controlled and monitored by computers which keep a check on elements like lighting and temperature or warning the occupants of dangers (Working with Older People, 2000). The Edinvar Housing Association has pioneered the possibilities of smart technology in a demonstration flat in their St Leonard's project in Edinburgh. The smart home can close and lock windows and doors, adjust the height of kitchen units and sinks, turn lights on, close curtains, flush the toilet, shut off the gas, send an automatic emergency call, monitor movement, and broadcast reminders, for example to take medication (Scottish Homes, 1999b). The opening/closing of windows and access in the kitchen are just two features that interviewees in this study identified as causing them problems within their home. Both windows and kitchens are now able to assimilate smart technology, enabling wheelchair users to live more independently within the spaces of their home. As Dewsbury and Edge (2000) have argued 'lifetime homes, barrier free and universal design should be reconsidered in the light of the development of smart home technology so that ...smart technology is an essential part of the design process and not an after-thought' (Dewsbury & Edge, 2000:2).

CONCLUSION

'Housing is an issue of critical importance for disabled people' (Herd, 1999) without access to a suitable home people with disabilities are unjustly denied many freedoms that able-bodied people take for granted. Out of the 50 wheelchair users interviewed, 6 were living in unadapted, inaccessible mainstream housing, a further 28, who were living in 'special needs' housing,

encountered design features that restricted their movement and ability to function within their house. The proliferation of barrier free standards, within the framework of social inclusion, requires a flexible redefinition of what is now called 'mainstream' housing (Herd, 1999). '[I]mproving the accessibility and suitability of our constructed environment will require a basic shift in attitudes – for instance, viewing flat or ramped access ... as the norm .... Considering the age of the vast majority of buildings in the UK, this is a huge task, but wouldn't it be a wonderful start if most of the 4.4 million new dwellings (estimated to be needed by 2016) are accessible for all' (Disability View, 2001). It will take a number of years before the impact of the revised Part T of the Building Regulations will be experienced by people with disabilities in their everyday lives. However, the amendments are recognition that previous housing policies, framed within an ableist discourse, have not been egalitarian and have marginalised people with disabilities within society by restricting their access to certain places and spaces. The amendments to Part T can therefore be seen as partial evidence of how previous housing policies and practices are implicated in the social construction of disability and the socio-spatial exclusion of people with disabilities.

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[1] In 1989 SSHA merged with the Housing Corporation in Scotland to form Scottish Homes (Clapham & Smith, 1990).

[2] Applications can be made to the Scottish Executive to increase this maximum allowance, and such applications are nearly always granted (Scottish Homes, 1999a:17).

[3] The term mobility housing is now redundant and has been replaced by barrier free housing that has incorporated many of the standard features of mobility housing.

[4] In a 1961 report (Ministry of Housing and Local Government, 1961) Sir Parker Morris recommended changes to the definition of standard floorspace laid down in the Ministry of Housing and Local Government's design manual of 1952 and 1953. The Parker Morris standards increased the maximum floorspace for a five-person terraced property from 900sq. ft. to a minimum standard of 910 sq. ft. plus 50 sq. ft. for storage. It was not until 1969 that these floorspace recommendations were made mandatory (Cole and Furbey, 1994). Lifetime Homes in England conform to minimum Parker Morris space standards, although at least one commentator maintains that the space standards in Lifetime Homes compromise on Parker Morris storage

provision (Walker, 2001). In Scotland space standard guidelines conform with Scottish Housing Handbook Guidelines.

[5] I have retained Goldsmith & Kirby's (1977) use of the word 'handicapped', although not in common usage in recent disability literature, Goldsmith and Kirby (1977) use the word to convey the social construction of disability: the stairs were seen as disabling.

[6] The independent living paradigm's philosophy is similar to the social model of disability in that it rejects the medical model of disability. The paradigm emphasises that the problems of people with disabilities are not only physical, but also occur because of the unnecessary dependency upon relatives and professionals. The pathology is not in the individual, but in the environment and the unprotected rights which restrict the opportunities of people with disabilities (Dunn, 1990).

[7] As noted previously (Chapter 3) my sample of interviewees are not representative of wheelchair users generally, hence these figures (as with others presented in the thesis) cannot be generalised beyond this study group without further research.

[8] The number of housing association dwellings without double-glazing was disproportionately high compared to the overall high standard of design features in such properties (Table 4.5).

[9] See Appendix B for definition of mobility housing.

[10] Feminists have critiqued community care, arguing it is synonymous with care by female kin (Graham, 1994), and that women are carrying the burden of a more tolerant and inclusive society. Many women are (voluntarily/involuntarily) caring for relatives, but there is a deficit in the literature in that there is little consideration of the impact on men of caring for kin, for their wives, partners, children and grandchildren (see Arber & Gilbert, 1994). How are men coping financially, socially and emotionally with giving up a job, learning and carrying out domestic duties, caring for a loved one and how is their relationship with their wife affected? These questions are outwith the remit of this thesis but a study that investigated them would enrich our knowledge and understanding of community care, informal care and male/female roles and relationships within the home.

[11] The Disability Discrimination Act 1995 and amendments to the Building Regulations, Part T, are enforcing accessible standards in the construction of public and private spaces.

[12] Although people with disabilities will still encounter problems accessing the owner occupied market for economic reasons, and those already in the private market are likely to encounter problems maintaining the upkeep of their home (Easterlow *et al.*, 2000).

5

SHELTERED HOUSING: INSIDER AND OUTSIDER PERSPECTIVES

INTRODUCTION

The previous chapter examined physical barriers associated with the housing of people with disabilities through a discussion of the development of accessible housing. This chapter focuses on one particular type of housing, sheltered housing, and the associated social barriers experienced or perceived by interviewees. Place is exposed as an important constituent in the shaping of identities and perceptions that individuals have of different people and places.

THE DEVELOPMENT OF SHELTERED HOUSING

Sheltered housing is designed to facilitate independent living for older people by providing individual houses/flats clustered together with on-site formal support, through an alarmed warden system. In addition, a communal infrastructure exists to combat the loneliness and isolation that is often synonymous with the ageing process as people's lives become predominantly home based. Sheltered housing is, Fisk (1999) asserts, a present day derivative of almshouses. Drawing on the work of Howson (1983), Fisk demonstrates a direct parallel between almshouses and sheltered housing. A sixteenth century almshouse in Kent, for

example, comprised 19 dwellings around a 'sheltered' quadrangle. It included accommodation for a warden and sub-warden, and a hall, presumably used for communal activity. All these features are standard within sheltered housing today and were enshrined in the 1969 government document that gave such housing its stereotypical form, facilities and services (Fisk, 1999). Fisk employs the analogy of almshouses to demonstrate the design similarities with sheltered housing. However, there are further similarities: the concept of almshouses is infused with images of helplessness, deprivation and dependency, images that are also applied to some present day readings of the landscape of sheltered housing.

In a 1948 government housing manual the name 'sheltered housing' was attributed to housing schemes for older people that were located in sites 'sheltered from the wind' (Ministry of Health, 1948). It is doubtful whether over 50 years later housing planners assume the responsibility of siting sheltered housing in a sheltered location. Rather over the years the term has been interpreted to mean housing that can provide support and protection for people in old age. However, '[l]ocation was and remains a vital design factor' (Cope, 1999:306) for ensuring the occupants of schemes are able to lead independent lives. Drawing on the Ministry of Housing and Local Government Circular 82/69, Cope (1999) states that schemes should be located close to local amenities, shops, post office, health centre and to transport facilities. The security and independence of occupants of sheltered housing is enhanced by a warden service and communal lounge, these two features make the spaces of sheltered housing unique socio-spatial phenomena. However, this can lead to the social spaces of sheltered housing being imbued with and constructed from a

social discourse that stigmatises and marginalises older people and people with disabilities[1]. Thus in addition to the physical boundaries that delineate sheltered housing from mainstream housing, the social geography of sheltered housing creates imaginary boundaries that differentiate between bodies that cultural practices conceive of as normal and abnormal. A critical reading of the landscape of sheltered housing reveals how the social spaces of such housing can be seen to be implicated in the production and reproduction of prevailing cultural imagery of disability (and old age). That is sheltered housing provides a space for hiding abject bodies from normal society and thereby emphasising their difference from accepted norms.

The two interpretations of sheltered housing outlined above - a place that provides for independent living and a space that stigmatises - problematise the concept of sheltered housing by illustrating the tensions that exist between the phenomenon as an enabling and/or disabling social space. These contradictory interpretations of sheltered housing mirror the perceptions and experiences of such housing schemes held by interviewees contacted in this study. The multiple voices of the interviewees are explored below to provide a nuanced account of the significance of place and social discourse to an individual's reading of the landscape of sheltered housing. Two distinct groups emerged from the interview data: 'insiders', those living in sheltered housing and, 'outsiders' those living in non-sheltered housing. Outsiders perceived social disabling barriers, such as stigma, dependency and exclusion as grounds for contesting sheltered housing as enabling living spaces. In contrast, insiders did not share the negative

interpretation of sheltered housing perceived by outsiders, but experienced such housing as both enabling *and* disabling.

Dualisms play a prominent part in this chapter principally in distinguishing between insiders and outsiders. Despite drawing on postmodernist ideas and thinking the structure and content of the chapter are derived from the creation of this insider/outsider dualism. For whilst postmodernism attempts to engage with difference, rather than rely on dichotomous categories as a means to open up previously neglected aspects of geographical inquiry, dualisms persist and can be analytically useful in reconstucting data in a comprehensible form. The insider/outsider dualism is employed here to emphasise the fluidity of the identities of people with disabilities, and to demonstrate that there is no single, homogeneous disabled identity, but a heterogeneous mix of multi-layered identities that have a spatial component to their composition.

INSIDERS AND OUTSIDERS

Before moving on to discuss the dichotomous readings of sheltered housing held by insiders and outsiders, I want to provide some demographic background to these two groups of people. Thirty per cent of the interviewees were living in sheltered housing, and 54% of these people were under the age of 55, the youngest insider was 24 year old Sally (Figure 5.1). The ages of insiders and outsiders were similar, other than there being more 55-64 year old insiders than outsiders, and within the sample of 50 interviewees there was no-one aged between 35-44 years living in sheltered housing.

Figure 5.1 Ages of Insiders and Outsiders

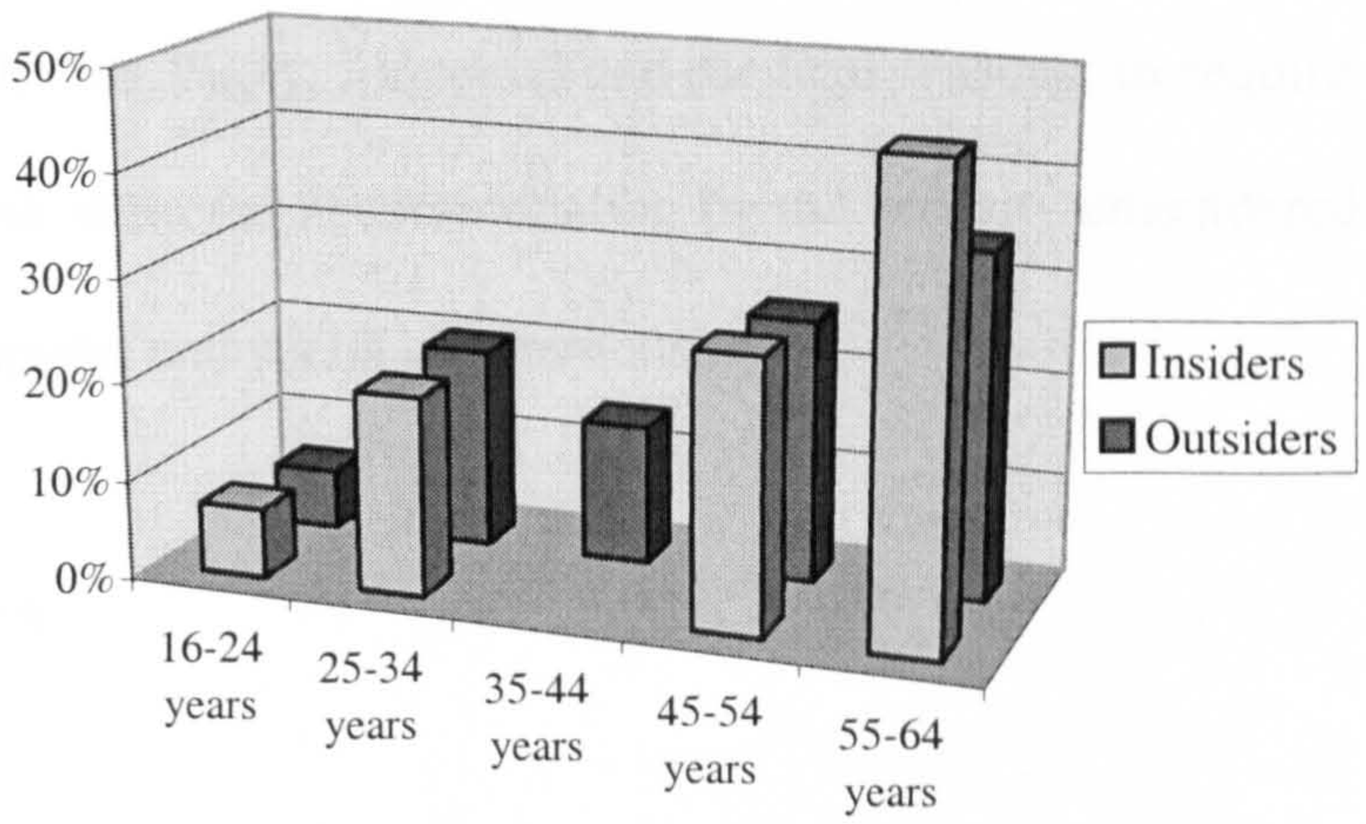
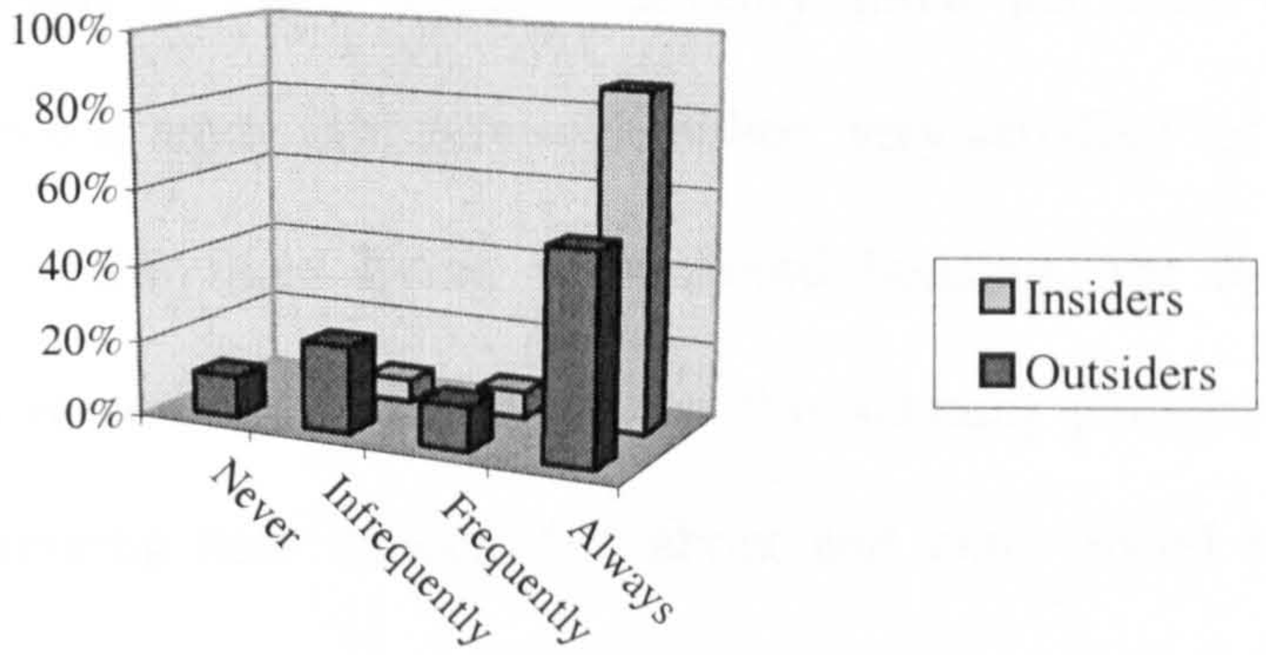


Figure 5.2 Insiders and Outsiders Use of Wheelchair Inside the Home



The percentage of males to females for outsiders was 31% to 69%, whereas amongst insiders it was 67% males to 33% females, almost a mirror image showing a much higher proportion of men moving into sheltered housing than women. In relation to wheelchair use, there was a higher percentage of permanent wheelchair users living in sheltered housing (87%) compared with outsiders (54%) (Figure 5.2). This suggests that within the allocation process people who are perceived to have the greatest medical need are being offered sheltered accommodation. When this finding is related to the number of insiders

living on their own (54%, compared to 9% of outsiders), a picture emerges of people who are likely, for social and medical reasons, to require or are attracted to living in sheltered accommodation by the security engendered by place-based formal support and social companionship.

INSIDERS

In a 1993 document Scottish Homes praised sheltered housing as a 'major success story' (Scottish Homes, 1993b) and research indicates that it is a relatively popular form of accommodation for older people (Anchor Trust, 1986, 1994; Thompson & Page, 1999). Seventy three per cent of the insiders interviewed in this study said they were either 'very satisfied' or 'satisfied' with their housing, 58% liked living in sheltered housing, yet remarkably, 93% wanted to move house. I want to address this seeming paradox in the sections below by exploring how insiders felt about and experienced life in sheltered housing and why so many of them, despite expressing satisfaction with sheltered housing nevertheless wanted to move.

Linked Warden Alarm System

One of the strongest magnets that appears to be drawing people with disabilities into sheltered accommodation is the place based support that is provided by a warden. The alarm system enables people to call for assistance by pulling one of the ceiling-to floor cords (usually located in the bathroom, bedroom, kitchen and living area) or by activating the alarm remotely by a pendant worn around the

neck. In sheltered housing[2] the alarm notifies the on-site warden that help is needed. However, outwith the warden's working or on-call hours sheltered tenants are transferred onto the local community alarm network and help is then provided from outwith the boundaries of the housing scheme.

A 1984 Age Concern study found 81% of tenants had not used their alarm system in the previous year, similarly a 1994 Anchor Trust study found 73% of Anchor tenants had never used their alarm system (Cope, 1999). Despite the reported low levels of usage of alarms, sheltered housing tenants valued the system for the additional sense of security it provided. This study found that the alarm system was perceived to be an asset for enabling insiders to live independently and was invaluable. Even if, like older people, insiders rarely, if ever, used the service.

Helen: When I first applied, I was living at mum and dad's, and for our peace of mind they said you're not moving anywhere if its not sheltered or something. So it gives them peace of mind and it gives me peace of mind knowing if anything does happen there's someone there.
Susan: Are you saying that having the warden on call is reassuring?
Helen: Well it's nice to know that if you landed on the floor, you're not going to be stuck there for ever and ever, you know you just have to pull a cord and someone will come and help you.

Helen, interviewed 6/2/97

Susan: Do you find having the warden useful and have you ever used the warden?
Gillian: I've used her once, but she doesn't come in every day, if I'm by myself, she'll like buzz me at 9am to see if I'm up and OK, we tend not to use her much, but knowing she's here, I wouldn't like to live in a house that didn't have a warden. If Philip goes out and I'm here on my own, I'm not really here on my own.

Gillian, interviewed 12/2/97

Helen and Gillian are both sheltered housing tenants, yet, the sense of security conveyed by an alarm system was not tied to sheltered housing. Outsiders living in houses integrated into mainstream society perceived their community alarm to be a preventative device. As Kevin says it's like an 'insurance policy'.

Kevin: I think it's a very good idea, because you never know when you're going to need someone during the day. And with both parents working.
Susan: So you are by yourself quite a bit?
Kevin: Yes. So it's like another insurance policy almost.
Susan: Have you ever used it?
Kevin: No but it's always good just to have for insurance.

Kevin, interviewed 2/4/97

Although both insiders and outsiders with an alarm system could see the benefits of having the technology, there are temporal and spatial differences in these benefits. Technology is essentially aspatial, that is it has the capacity to eliminate space and time. However, it is not the spatial and temporal characteristics of the alarm that are functional for insiders but the fact that their alarm is connected to the warden. The technology of the alarm is simply a device for summoning place-based help. It is the physical proximity of the warden that is critical. Insiders are reassured that during their warden's on call hours, help is very close by. In contrast, outsiders accept they may have to wait some time for help to arrive as Laura recalls:

The last time we used the alarm when he was at home (husband) it was night time. And we contacted them (ie used her community alarm) and they went and phoned my son, and it was half past twelve at night, he was in his bed, he'd been out for a drink, so he couldn't take the car, so he had to take a taxi to come here.

Laura, interviewed 23/1/97

Incidents like the one Laura talked about have led her to question whether the community alarm is really beneficial for people like herself who have family living close by, and who would be contacted day and night by a control centre to help out in an emergency. Now that Laura understands how the community alarm system works, she thinks she may contact her son directly if she needs help in the future, and thereby save time going through the control centre.

For insiders the physical proximity of a warden coupled with the technology of the alarm system engenders within them a sense of security and independence. However, the provision of a warden alarm system appears to be encouraging dependency on the alarm to generate help in an emergency, and in the process it appears to be inadvertently discouraging people from interacting with their neighbours and developing positive neighbourly relations. This suggests that the combination of the warden and alarm could be threatening traditional neighbouring patterns of reliance on neighbours for help in times of need (Keller, 1968; Robinson & Abrams, 1977). It is possible that the introduction of more technology into the home environment will further weaken the need to socialise and build trusting, reciprocal relationships with neighbours. Cope (1999) for example is concerned about the power technology can and may have on our lives, to the detriment of social interaction. Alarm systems, she argues, may 'undermine rather than enhance the independence of older people, and the temptation may be to rely on technology rather than human contact' (Cope, 1999:307). As the following quotations demonstrate the alarm system may be working against the ethos of care in the community by failing to encourage social

interaction in that it does not meet the social needs of the people that care in the community aims to include and integrate into local communities.

> *I think community care is all wrong. Like see now they're putting people from hospitals into the community and they're lost, most of these people have been institutionalised for years and years and they give them a house and they just get lonely ... when all they've got is that bit of string.*
>
> Gillian, interviewed 12/2/97

> *Susan: Do you find that people are generally helpful around here and that you have people to rely on if need be?*
> *Laura: No. Nobody.*
> *Susan: Does that concern you that you don't have people around you that if the need arose you could call on for help?*
> *Laura: Well I've got the community alarm.*
>
> Laura, interviewed 23/1/97

It is difficult to deduce whether the diminishing neighbouring amongst interviewees results from the alarm system or is simply a manifestation of modern neighbouring patterns. However, any negative impact that may be attributed to the warden alarm system is perceived by insiders to be outweighed by the accrued benefits the system confers to them. The alarm system is proving invaluable to people with disabilities and the physical proximity of an on-site warden further enhances an individual's sense of security and independence. Thus, whilst the alarm system may encourage dependency on the technology (Cope, 1999) it also encourages and engenders a greater sense of freedom to live away from the parental home or a residential home. There may however be an alternative explanation as to why there is limited social interaction occurring between insiders and their neighbours that is related to other unique features of

sheltered housing: the communal lounge and the concentration of older people in an enclosed space.

Communal Lounge

The communal lounge was designed to act as a focal point within sheltered housing for neighbours to participate in mutual social activities. It was designed to facilitate and encourage social interaction between tenants and thus prevent older people leading lonely lives or having to travel outwith their neighbourhood for regular social activities.[3] The use of communal lounges by older people has been found to be high in sheltered schemes (Anchor Trust, 1986, 1994, cited in Cope, 1999). These studies suggest that the communal lounge is serving the needs of older people quite well, probably because it has been designed and constructed specifically to function around their needs. However, the following section illustrates how the social construction of the communal lounge, as a social space for older people, appears to be excluding both socially and spatially people with disabilities from their place-based community.

Hudson argues that 'the ready availability of support combined with individual facilities and the prospect of social contacts' (Hudson *et al.*, 1996:20) are what attract people to sheltered housing. This appears to be true for people with disabilities as well as older people. For example, when I met Alice the idea of sheltered housing appealed to her. In particular she had high expectations about the social benefits that would accrue to her as a sheltered housing tenant. She was optimistic that if she were offered a house in sheltered housing, it would

enable her to re-establish a social life, to get out and be a part of her local community. Helen, like Alice, anticipated that sheltered housing would offer her a 'ready made community' with regular communal activities that she could participate in and would make her feel like she was living 'in a community'. Both Helen and Alice are single, they do not drive and, in common with over 80% of people with disabilities in Britain, they are unemployed (Herd, 1999), consequently they lead principally place based lives with irregular excursions into other social spaces.

> *Alice: Sheltered, there's like a community, if you know what I mean, they get together, do things together.*
> *Susan: Is that important to you, to have a sense of community of doing things together?*
> *Alice: It's good to meet with people and mix with people, you don't feel so lonely then.*
>
> Alice, interviewed 14/1/97

> *It's the people and the age and having a complex that you know you can go to and you know that you are going to have a good time. Where you can go and you know there will be things for all different age groups whether they're disabled or able-bodied, where everyone can go to the complex and there's a great community spirit.*
>
> Helen, interviewed 6/2/97

The absence of social support for insiders in sheltered housing appears to be exacerbated by the large number of single people living in sheltered housing. A substantial number of insiders (54%) were living on their own. This is significant since the social needs of people living alone are inevitably different from those of couples and families. In a 1995 Joseph Rowntree Study, it was found that a large number of people with disabilities wanted some form of sheltered accommodation, and that all these people were women who were

currently living alone. This suggests that the social component of sheltered housing is important for single people, yet it appears that people with disabilities are being marginalised by the majority population - older people - within sheltered housing.

Physical boundaries demarcate the spaces of sheltered housing from mainstream society, but insiders implied that there are further imaginary boundaries delineating inclusive and exclusive spaces within sheltered housing schemes. Helen, for example, makes innuendoes that the problems people below retirement age are facing in sheltered housing can be attributed to it being a socially constructed space exclusive to older people. It would appear that an internal and largely homogeneous majority (with regard to age)[4] are 'patrolling' communal lounges and feel empowered to erect boundaries which determine the inclusion or exclusion of people to communal activities. Consequently insiders were feeling that they 'don't belong' and are unwelcome in social spaces that housing providers have designated and deemed as suitable for them. Gillian's experience makes this point quite explicitly. Gillian, unlike the majority of insiders, is part of a family unit, which includes her husband and three children. According to the 'pensioners' only Gillian is allowed into the communal lounge, but she wants to do things as a family or with her husband (who is also her full-time carer). Gillian epitomises how people with disabilities can be discriminated against and excluded from participating in social activities in sheltered housing.

> *They have a communal lounge right, they built it with these houses right, but for pensioners right. All the houses round here are pensioners, other than me and the girl next door, everyone else is over 65. So I mean*

> *there's no kids, so it's bad for the kids. So this lounge what they did right, they had a tenants meeting when we moved in, the pensioners said, we don't want kids, so my kids can't get in.*
>
> Gillian, interviewed 12/2/97

Furthermore, Gillian had hoped to find that she would be able to identify with and share experiences with other people with disabilities when she moved into sheltered housing, but she is disappointed with the reality of social interaction within her scheme.

> *Susan: What do you feel about living in this type of a housing scheme?*
> *Gillian: I thought it would be good, coz there'd be other people with disabilities, but in saying that none of them mix, you know they all keep themselves to themselves. You know like it's not very good, eh it'd be nice if you all, coz there is so much you can you share like, you know bad days and good days.*
>
> Gillian, interviewed 12/2/97

In contrast to the experience of sheltered housing, the sharing of experiences of 'good days and bad days' that Gillian had anticipated finding in sheltered housing, appeared to be occurring in the small scale clustering of non-warden linked wheelchair housing. The clustering of five or six purpose built houses within mainstream housing was found to be creating a framework that fostered positive social interaction between neighbours. The neighbours were able to understand and support each other through sharing disabled/disabling experiences. The strong friendships that had been established between neighbours created an informal network of place based care and support. This system of informal care partly eliminated the need for place-based formal care, ie a warden.

We'd all help one another, one of the partners has an able-bodied partner, which is good. Like it's the lady next door who is disabled and still works, the lass up the road, I don't know them as much, her young daughter is disabled, and then the man in the first house is disabled and they're awfully nice, if you need anything you know we could go to one another, coz there is always one partner there to help, awfully good, anything.

Lucy, interviewed 24/1/97

The design of a few purpose built houses clustered together appeared to be playing a significant role in enabling people with disabilities to build a trusting, supportive and inclusive space for themselves. Unlike sheltered housing this type of housing is designed to cater for people with disabilities of a variety of ages. Two of the advantages to people with disabilities of living in such housing are first, all of the houses of their immediate neighbours are physically accessible. This enables them to move freely into and out of their neighbours' houses in frictionless space. Secondly, they can identify with their neighbours, they share experiences and support each other by understanding the ups and downs of living with an impairment.

I think even in my last place where I was, overall they were good, but they were able and always on the go. And I said, 'Now would they understand the same?' You know, and that's a good thing, one good thing about it, because you're able to talk you know, and they understand, it's good.

Lucy, interviewed 24/1/97

Susan: What do you think about living in an area where there are just a few disabled people living together?

Liz: It's not bad I went to look at a house in Blackwood Court (sheltered housing scheme) when I was first looking for houses and didn't like that idea at all because it was a warden complex, I didn't want that I felt I might just as well stay at home if I was going to move into a place like that. I know some people do need it but its not what I want. 'Em, so moving here there is no warden, you have your own independence, you come and go as you want, you know which is really what I wanted, 'em and there are disabled

people near by so everyone knows what you are going through, you're not sort of isolated.

Susan: Do you think that is important that you understand each other?

Liz: Yeah, yeah, like we all get on well with one another, and if any of us is going through a bad patch we know we can rely on one of the others you know, which is good. Fortunately we haven't all been going through bad patches at the same time, I don't know what would happen then. 'Em it is good to have somebody, especially a few younger people as well you know, because normally its all older people in this type of housing.

Liz, interviewed 13/3/97

The positive social experiences of Lucy and Liz of living in an accessible house close to other people with disabilities illustrates the importance of designing houses that facilitate socially active and independent lives. Great strides have been made in the design of houses for wheelchair users over the last 50 years. This is reflected in the fact that only a few insiders encountered problems with the design of their house, although physical barriers in the form of steps up to communal lounges and other tenants' houses (ie non-adapted houses) prevented them from participating in social activities and visiting their neighbours. But the message conveyed by insiders was that the social barriers that they encounter are causing them the greatest stress and restrictions on their lives. Insiders felt that service providers tended to overlook their social needs and saw the 'bricks and mortar' and design features of houses as the principal factors that determined the allocation process. With hindsight Helen believes someone from the council (either social work department or housing department) should have enlightened her to the social reality of living in sheltered housing rather than focusing exclusively on the benefits of a suitably designed house.

You see I get very, I'm very ... There is one thing I really disagree with, that's social workers, or OT's (Occupational Therapists) and the

wardens, when I first came here ... I admit I thought it was the right move, and from April to November no-one said anything. I thought OT's and social welfare are bound to have the information and I'm quite sure if they thought a bit more laterally they could think about how they would feel if they were in my situation. But I get the feeling that you're just a name to them and when they get you allocated that's their job over and done with.

Helen, interviewed 6/2/97

The reality is that service providers are largely unaware of the social needs of people with disabilities and therefore their experiences and expectations of sheltered housing.[5] Consequently the allocation process can be interpreted as reflecting an ableist discourse that embodies a fear of difference and disability. Wilton (1998:174) states '[s]patial separation facilitates the maintenance of social boundaries since it reifies perceived social differences between same and Other'. Sheltered housing appears to be facilitating the maintenance of perceived boundaries between normal and abnormal bodies by providing a space where people are hidden, and outwith the public gaze.

They provide you with all the adaptations you need, but keep you out of sight, always in the corner of schemes, always separate. I've always believed in integration not segregation.

Deborah, interviewed 20/1/97

Social Interaction in the Spaces of Older People

The definition of oneself in relation to others (as different or the same) is embedded in our psyche from childhood and influences how people think, behave and perceive others (Sibley, 1995; Wilton, 1998). The problems described above, associated with the heterogeneity of ages in sheltered housing,

illustrate an embedded social discourse that is premised on a fear of difference. It became evident whilst I was talking to insiders that many of them felt older people were generally wary of young people with disabilities and found it difficult to comprehend that younger people may also be frail and have mobility problems like themselves. For example, Penny and Liz had felt out of place and unwelcome when they had tried to acquire more information about their physical impairments by attending a meeting for people with arthritis. The 'gatekeepers' to the individual meetings were older people. Both Penny (39) and Liz (31) were perceived by the gatekeepers to be outsiders, to be too young to gain entry into their exclusive 'arthritic space'. After a lot of negotiation, that required Penny and Liz to self-identify as disabled, and convince the gatekeepers that they had arthritis, they were allowed into their respective meetings. The experience surprised and disappointed Liz and Penny. They did not find an inclusive space within which knowledge on their specific medical condition could be gained in a mutually supportive and understanding environment and where experiences could be exchanged. Rather they found a hostile, exclusive group of people that wanted to marginalise and exclude fellow arthritis sufferers based on their difference[6]. As Penny recalled,

> *Penny: I used to go Arthritis Care, they had a meeting once a month. But I tried it a few times right at different times right. The very first time I went I was actually turned away at the door, right, I thought I couldn't believe it, because I've got arthritis and I thought I want to find out more about this, how can I help myself, what I can do to stop all this pain. So I goes into one of these meetings and the woman says to me, 'Wait a minute you must be in the wrong place', I says 'What do you mean?' She says this is for arthritis people. I says, 'But I've got arthritis', she says, 'Are you sure about that?', I says, 'Yeah, I have got it'. And she says*

'Well I dunna ken about this'. But eventually she let me in, ken after about half an hour of arguing.

Susan: What was the problem?

Penny: She just thought I didna have arthritis, for some reason, I dunna ken. When I sat through it, it was like a talk, I sat through this talk, and then I had a cup of tea or something after it, and then she says to me, 'Now you won't be coming back next time will you?' I thought ken what's the problem?

Susan: Was everybody else older?

Penny: They were older.

Susan: So she perhaps thought that a young person doesn't have arthritis.

Penny: Ahh, it was dead strange like, so then I left it coz I thought I was worried about going back. Then I said to my daughter you come with me the next time, she goes 'ehh?' So the next time I went, I didn't get like refused when I went through the door, but everybody stared, wondering ken what are you doing here. I stayed had my cup of tea, and then thought no I'll not go back. I felt really awkward, and like I shouldn't have been there.

Penny, interviewed 5/2/97

The experiences of Penny and Liz and those of insiders of life within sheltered housing suggest that people with disabilities are struggling to find spaces that they belong in, are empowered in and can call their own. Older people in sheltered housing appeared to have found a space that they could control and demarcate the boundaries to inclusion and exclusion. Social and spatial factors are interwoven into this process of social inclusion experienced by older people, and into the process of social exclusion experienced by people with disabilities. In this instance the spatial factors refer to the spaces of sheltered housing, and the social factors to the older people who appeared to be using their privileged position of being in the majority to influence the lives of the minority (people with disabilities). What this seems to illustrate is that the social dynamics of an enclosed space (ie sheltered housing) are capable of mirroring and reproducing on a micro-scale the majority/minority, same/Other power relations that are exercised in wider society.

One of the consequences of the relationship that appeared to be established between people with disabilities and older people within sheltered housing was that very little social interaction occurred between the two groups. The principal barrier that appeared to inhibit neighbourly interaction was associated with age. The older tenants did not identify with their younger neighbours and vice versa. This dichotomous relationship is manifest, as discussed above, in people with disabilities feeling unwelcome and out of place in the communal lounge. Furthermore, interviewees felt unable to socialise in a meaningful way with their neighbours because they shared little in common. As Helen (35 years old) maintains, the age difference between her and the other tenants has excluded her from developing a local social network.

No, no-one told me when I came here that this is a colony of elderly people, which means the grey hair, white hair people. There are only really two people that I can talk to here. So I visit Jill on Monday and I see Elaine now and again. But I sometimes go into the nursing home on the corner and I like it because they're a lot younger there, even though they've got problems, ... it's a bit of a change to meet someone who isn't repeating what they say every five minutes. This was a major mistake coming here. ... A year at the complex comprises of a fund raising bingo, a Christmas party, a concert which is old folks singing and I'm not very enthusiastic about.

Helen, interviewed 6/2/97

In addition to the barriers to social interaction caused by the disparity in ages of tenants, further barriers exist in the very nature of sheltered housing being home to new populations, rather than established, supportive communities. People are drawn to sheltered housing from a variety of social backgrounds, and for some people it is their last home, for others it is a bridge between their previous home

and a residential/nursing home or hospital. The transient nature of sheltered housing populations is reflected in 60% of insiders having lived in sheltered housing for less than 5 years, compared to 33% of outsiders in unadapted housing, 27% in purpose built housing and 22% in adapted housing. Crow and Allan (1995, cited in Atkinson and Kintrea, 2000) have studied the factors that help people moving into a new neighbourhood become attached to existing communities. The most important factors they found were temporal (length of residence) and socio-spatial (the perceived social distance between the newcomers and the existing community). Certainly within sheltered housing it appears that social rather than physical proximity (Crow and Allan, 1995) is the key to engendering or preventing social interaction. Older people it was found are producing exclusive, 'ageist spaces' by creating social barriers between themselves and people with disabilities based on their age[7].

Summary

Insiders appear to be looking for formal support, companionship, and a sense of community within sheltered housing. Furthermore, they value the unique features of sheltered housing: the on-site alarmed warden service and the communal lounge. However, the social and spatial design and construction of the majority of sheltered housing schemes appear to be excluding people with disabilities from participating and becoming a part of a place-based community. This tension between sheltered housing being both an enabling *and* a disabling environment explains why 93% of insiders wanted to move house but wanted to

move to a house that could provide them with similar levels of support and security, plus the potential for social interaction.

I now want to move on to consider outsiders' perceptions of sheltered housing and the concept of stigma. For stigma was found to be fundamental in differentiating between insiders and outsiders experiences of sheltered housing. Insiders did not experience or perceive sheltered housing to be stigmatising[8], whereas outsiders appeared to be using the cues that were available to them from prevailing social discourses to read the landscapes of sheltered housing as stigmatising.

OUTSIDERS

Outsiders contested the view that sheltered housing is an enabling living space. The segregation of sheltered housing from mainstream housing was seen by outsiders to reinforce social segregation. In other words, the spatial was seen to be impacting on the social. Sheltered housing was viewed as stigmatising, providing for the needy and weak in society, and was thus seen to be reinforcing negative images of people with disabilities. 'Places are avoided or viewed with apprehension where a stereotype of a despised group combines with and reinforces a negative stereotype of place' (Sibley, 1998:120). In order to overcome the stigma that outsiders saw as being synonymous with sheltered housing, they chose to live in 'able-bodied' spaces. They wanted to feel 'normal' and not to be reminded of their disability and marginalisation from society by living with other people with disabilities in segregated spaces. One

way that outsiders perceived this could be achieved was through living in integrated housing where their difference from the norm would, they anticipated, be less obvious.

Kevin: No, no, in fact I feel safer that way, (integrated into mainstream housing) because I don't like these rows of houses where you've got all disabled people. Coz it goes back to the stigma.
Susan: So you'd support the notion of integration, and people living independently in the community?
Kevin: Yes. I find it is very, very important for me to meet others, non-disabled people.
Susan: Do you find you understand other disabled people, that you have something in common with them?
Kevin: I've got something in common with them, but that's where it stops. I like to get away from it.
Susan: So when people talk about a community of disabled people, that's ...
Kevin: Oh, no, no, that is not on.
Susan: Why is that?
Kevin: Everyone deserves to be treated as an individual.
Kevin, interviewed 2/4/97

For Kevin integration means being a part of able-bodied, 'normal' life, whilst segregation, he argued, reproduced negative imagery of people with disabilities. Kevin seeks to disassociate himself from the conventional association that links different, abnormal people with different, special spaces. In other words, spatial segregation was perceived as reinforcing negative socio-cultural imagery. Kevin says he prefers to, and wants to, identify with able-bodied people, and rather than celebrating his difference he seeks to disregard it in mainstream society and live 'a fantasy of social inclusion and participation, albeit by proxy in the wider society' (Wacquant, 1993:373). Kevin may feel physically 'out of place' in able-bodied space but, psychologically he feels confident, included and able to lead an independent life. In addition, living in integrated housing eliminates or lessens a

number of social barriers that enable outsiders to direct their energy into other areas of their life.

For Kevin and others like him, place appears to matter in the construction of their self-identity. Kevin anticipates feeling 'out of place' in sheltered housing as he doesn't want to be identified with, nor does he himself identify with, the disabled imagery that is inscribed onto and thus associated with the spaces of sheltered housing. Furthermore, Kevin believes he couldn't be 'an individual' in sheltered housing arguing that, outsiders and support staff would always perceive him first and foremost as a disabled person rather than moving beyond that weighted imagery to see a person who happens to use a wheelchair.

Susan: What about sheltered housing, if you were offered a house in a sheltered scheme, how would you feel about living there?
Carol: No way hosè, no way. ...
Susan: Do you think people see this house as being a disabled house, and does that concern you at all?
Megan: Well I dunna feel that this, it might.
Carol: It's not a disabled house.
Susan: You don't feel that it's visibly different to ...
Megan / Carol: No, no.
Carol: No, because the neighbours treat us as an equal family and basically that's it.
Megan: There aren't plugs and like we don't have to walk over a mat in the morning.[9]

Megan and daughter Carol who is also a wheelchair user, interviewed 28/1/97

Identities are never created in a vacuum, they are relational, they are influenced by society, individual people and spaces and places. The message conveyed by Kevin and Carol is that they predicted that living in sheltered housing would have a fundamental and negative impact on their identity. As Carol says living

where she does makes her feel like she belongs to her place-based social networks, her neighbours accept her and make her feel included and part of mainstream society. Thus the physical appearance and location of Carol's house is interwoven into the process of negotiating her identity. The welcome Carol receives from her neighbours appears to help her perceive her purpose built house as normal and non-stigmatising, whereas the general impression outsiders conveyed about sheltered housing was that it was stigmatising and different. It is clear that outsiders perceived sheltered housing as limiting and restrictive: limiting their independence and restricting their ability to mix with normal society and be accepted (see Nocon & Pleace,1998). Outsiders imply that sheltered housing essentialises and homogenises the individual needs, identities and interests of a heterogeneous group of people. Thus by exaggerating disabled people's difference from a culturally accepted norm of an able-body, the segregated spaces of sheltered housing become synonymous with a disabled identity that is, a disabled identity that connotes negativity, difference and stigma. The spatial contingency of identity formation, that is evident in the experiences of insiders and outsiders, reveals the power of place to produce and reproduce boundaries to exclusion and inclusion. The imagery of spaces that are stigmatised becomes reified into imaginary boundaries delineating those who belong from those who do not belong. It is clear from talking to outsiders that they did not want to be associated with spaces that society perceives as separate and different from the norm.

At all scales, from the personal to the global, spatial demarcation is a vital component of an ordering process by which forms of difference are created and

separated (Dear et al, 1997). Imaginary and tangible boundaries, perceptions and experiences of places do not always and need not be consonant, but they influence how we read landscapes and who we include and exclude, consciously or unconsciously, from our own living spaces.

> *... for me sheltered housing has the stigma attached to it. 'Oh we're no goin' near that scheme, that's got, its all disabled people'.*
>
> Kevin, interviewed 2/4/97

Comments like Kevin's have been extended into opposition to the building of 'special needs' housing in 'normal' neighbourhoods. Such opposition to the locating of community care homes and sheltered housing in communities is part of Not-in-My-Back-Yard (NIMBY) syndrome. The next section will consider the role of the NIMBYism in the study area of Dundee and more generally as a 'critical social dynamic [that] has limited the ability of deinstitutionalisation to secure justice for disabled people' (Gleeson, 1999:156).

Not In My Back Yard (Nimby) Syndrome

The NIMBY syndrome has been extensively researched in the US principally by Dear (see Dear 1977, 1981, 1992; Dear *et al.* 1977; Dear *et al* 1980), but British geographers have also shown interest in the subject (see Burnett & Moon 1983; Locker et al. 1979, Moon 1988). Although geographic analysis of NIMBY has mainly focused on people with mental impairments, Gleeson (1999) introduced the topic into general disability studies and offered two fundamental explanations for NIMBY, the first being economic and the second, social.

The commodity value of residential land in capitalist societies is a powerful influence on the social interests of owner occupiers and home purchasers (Walker, 1981). Owner occupiers fear that the presence of abject bodies or the spaces occupied by such people in their neighbourhood would lower the value and thus the exchange value of their principal economic asset, the home (see Walker, 1981; Plotkin, 1987; cited in Gleeson, 1999). Gleeson (1999) draws on a 1995 British High Court ruling (*The Times*, 21 September 1995:2, cited in Gleeson, 1999:158) to illustrate the enduring 'political-economic potency of NIMBY sentiments and their capacity to constrain disabled people's choice of living environment'. The British High Court ruled against the right to freedom and choice in the housing market for people with disabilities by awarding compensation to a set of neighbours for a fall in property values after a local health authority established a care home in the immediate vicinity (Gleeson, 1999). This High Court ruling illustrates how the hegemony of an ableist discourse influences the way people perceive special needs housing by affirming the economic rights of owner occupiers over those of people with disabilities to live in the community. This is despite a substantial body of geographic (see Dear & Taylor, 1982, Wolpert, 1978) and other social scientific evidence from a variety of countries (see Consulting Group, 1992) which shows that special needs housing tends not to affect residential property values in the medium to long term (Gleeson, 1999). Citing Dear's (1992) work, Gleeson (1999) argues that NIMBY reactions are expressions of more than simply a concern for property exchange values.

> The 'NIMBY mind-set is one powerful expression of the disabling imaginary, an anxiety about 'unruly bodies' that do not correspond to dominant constructions of safe and desirable forms of embodiment. Seen in this light, the NIMBY phenomenon emerges as a powerful cultural-material force that has helped to reinforce the disabling socialisation of embodiment in recent and contemporary Western societies'.
>
> (Gleeson, 1999:159).

In Dundee there appears to be latent opposition to the blurring of the boundaries or the elimination of the boundary between previously demarcated able-bodied space and disabled space. Despite the concerns of owner occupiers with property values (Walker, 1981), social renters were found to be more likely to have experienced negativity and opposition from their neighbours, than owner occupiers. This suggests that the fundamental objection of neighbours was to the presence of disabled/abject bodies in their local spaces, rather than fearing their presence would have a negative impact on the exchange value of their properties.

> *So things got worse and worse and worse we had to move house, and the first house that we got, the lady next door (Megan sighs) didn't want people in wheelchairs living next to her. She threatened us by saying she was going to set her dogs on us if we lived there.*
>
> *Megan, interviewed 28/1/97*

Growing interest by geographers in psychoanalysis (see Sibley, 1995, Pile, 1996, Wilton, 1998) provides fertile ground for understanding NIMBY reactions. Wilton (1998) suggests that negative opposition or NIMBY sentiments symbolise the division between self and Other, because the physical proximity, which sparks NIMBY, requires individuals to challenge the fragility of their own conceived normality. When people are confronted by disability in their everyday lives, it appears social distance may gradually diminish between the able-bodied

and disabled. Liz, for example, lives in a row of five purpose built houses for wheelchair users that are integrated into a street of otherwise mainstream social houses. When Liz first moved into her house she experienced initial hostility, curiosity and the creation of imaginary boundaries by her able-bodied neighbours. The boundaries were produced and reproduced by the able-bodied community to maintain social distance between themselves and their disabled neighbours when the physical distance between them had been erased. Yet Liz found over time that these boundaries began to crumble when her able-bodied neighbours discovered that the people with disabilities were leading normal lives and posed no threat to themselves, their neighbourhood, nor the identities of the able-bodied. Physical proximity and time appeared to change the attitudes and perceptions of the able-bodied neighbours.

> *At the beginning they looked at them and thought 'Oh they're disabled houses, must keep away'. But not so much now, because they can see that we're capable of looking after our own house, of doing the majority of things ourselves, you know, so it's not like that now. Again they're there if you need them, you just have to shout. So yeah, at the beginning they were very against us, it was like all the rejects were going to be coming to live in here. It's not like that now, people accept you, they can see, like I hang out my washing they hang out their washing.*
>
> Liz, interviewed 13/3/97

The findings of this study demonstrate, as has earlier research (Wilton, 1998, see also Arens 1993; Gardner et al. 1982; Wahl 1993), that a majority of community members learn to eventually accept 'special' facilities and their inhabitants. This is an important point since it confirms that people's conceptions of difference are socially constructed and consequently they can be challenged and changed through physical proximity (Dear et al, 1997; Wilton, 1998) and over time.

Engagement with the Other, what bell hooks calls 'repositioning', can thus lead to an understanding, and the rejection of a stereotype and weaken concerns with threats to the boundaries of community (Sibley, 1995:29). In other words, spatial and temporal factors can influence perceptions of difference and social interaction and the social inclusion of abject bodies. The contraction of space and expansion of time 'forces a reconceptualisation of the abject ... as part of the social/psyche – since it can no longer be distanced' (Wilton, 1998:182). An understanding of the spatial and temporal contingency of people's conceptions of difference by service providers could influence future housing decisions for people with disabilities.

The characteristics of NIMBYism discussed above are associated with two groups of people, one group opposing the presence of another. When the scale is reduced to an individual being perceived as different and out of place, it is easier, Sibley (1995) argues, to accept their difference. Stereotypes 'often include elements of place so that discrepancy or acceptance depend on the degree to which a group stereotype matches the place in which it is located' (Sibley, 1995:100). When the abject body is 'out of place' its context is lost and it is more likely that boundaries to social inclusion will be weaker. For as Kevin found disassociating himself from sheltered housing and living in an adapted house integrated within mainstream housing, helped him lose his disabled identity and feel assimilated and included in society. When the abject body is 'out of place' its context and social imagery is largely diminished, leading to the weakening of the boundaries to social inclusion. Thus place and housing create significant social cues that feed into the construction of identities and the construction of

socio-cultural norms and stigmas. Fundamentally then, space is a crucial component in the formation of identities and individual's experiences of health (Sibley, 1995; Dyck, 1999; Elliott, 1999; Wilton, 1999).

Trial Flats in Sheltered Housing

Most of the comments made by outsiders about sheltered housing were based on their perceptions and their anticipated outcomes of what it would be like to live in such housing. However, some outsiders had insider experience of living in sheltered housing gleaned from an ephemeral period spent in a trial flat, specifically, a Margaret Blackwood Housing Association (MBHA) trial flat. The trial flat is an accessible flat located within a sheltered housing scheme and it is available to help individuals decide if they want to and/or are able to live independently. Outsiders who had spent some time in the trial flat suggested that the flat itself may be partly responsible for perpetuating the negative imagery associated with sheltered housing.

The MBHA trial flat is located within a closed complex that is entered through a single, communal door. The complex itself is situated within a larger sheltered housing scheme composed of individual houses. The criticisms that outsiders had of the trial flat stemmed from its location in the closed complex, and the size of the flat. Some people found the trial flat was too small (see also Fisk, 1999) and questioned whether it had been designed for wheelchair users. It would appear that there is a need for a trial flat, but one that is larger and integrated into

mainstream housing or sheltered housing, and not situated within a closed sheltered complex.

> *They have got a, well you know where Ninewells Hospital is? well they've got Blackwood Court. I went there for a month to prove that I could make meals for myself and live by myself, it was a very long month. The trial flat is way at the end of the building so you're away from everyone. Even if you want to go to the phone it's a major expedition, getting to the phone. But I think just because the trial flat was way away. I think living with everyone being handicapped I'm not sure how I'd feel. Maybe it'd be OK, maybe it's be a bit depressing, everywhere is a bit depressing really.*
>
> Beth, interviewed 6/6/97

> *Susan: Apart from the flat itself, what did you think about the location and the housing scheme at Blackwood Court?*
> *Liz: Oh the rooms were tiny. For disabled, I thought how the hell are you supposed to manage a wheelchair in this, you know for being built as a disabled place, this was in the complex area where I was offered a house, with the warden, and the rooms were tiny, absolutely tiny. They had like a double bedroom, perhaps you'd get a double bed in it, and a bedside cabinet, but you wouldn't get a wheelchair in it as well, and the single bedroom wasn't any better. The kitchen was tiny, tiny, it was maybe a third of the size of my kitchen, there's no way it should have been, you know, whether it was meant for people with mental disabilities I don't know, but there was no way you could take a wheelchair in it. But it was terrible, you know.*
>
> Liz, interviewed 13/3/97

> *Susan: Have you seen Blackwood Court?*
> *Megan: Yes.*
> *Susan: What do you think of it?*
> *Carol: (Shakes her head).*
> *Susan: You wouldn't want to live there?*
> *Carol: I don't like the thought of being locked in, I like to be able to unlock my front door.*
> *Susan: They have got houses as well as the flats in the complex.*
> *Carol: I know but, no.*
>
> Megan, interviewed 28/1/97

In addition to sheltered housing being perceived as stigmatising it is often perceived as institutional, and associated with institutionalised regimes. The

work of Fisk (1999) and Clapham and Munro (1988) has questioned the appropriateness of institutional models of sheltered housing generally, and specifically those schemes with internal access to flats (ie MBHA trial flat). Their work has called for fuller integration within mainstream society. Outsiders who talked of 'being locked in' and having 'to walk over a mat in the morning' provide vivid clues that suggest sheltered housing schemes are accommodating communities under surveillance. The final section of this chapter explores the link between the shunning of sheltered housing by outsiders and the perceived loss of independence they associate with institutional forms of living.

Institutional Forms of Living

Emerging from the debate on outsiders and insiders is the central role of care, support and help for people with disabilities. Insiders were reassured that if they needed help whilst at home, the warden was close by. Whereas outsiders appeared to contest the concept of sheltered housing on the grounds that it perpetuates an institutionalised approach to housing, that it creates a community under surveillance (Fisk, 1999; Middleton, 1981). Bentham's panoptican, adopted by Foucault (1977) as a surveillance mechanism for monitoring prisoners, captures the essence of the fears held by outsiders of a warden observing, monitoring and intervening in their everyday lives.[10] Middleton (1981) was one of the first researchers to condemn sheltered housing arguing that it was a myth to pretend that it helped to maintain independent living when it involved moving to a community under surveillance. Middleton stated that 'whether this sacrifice is worthwhile in return for the benefits gained is another

issue' (cited in Fisk, 1999:35), but it is this very 'issue' that divides insiders and outsiders. The former (insiders) focus on the 'benefits' of sheltered housing, whilst the latter (outsiders) are unwilling to make the 'sacrifice'. Outsiders ultimately perceive sheltered housing as "abnormal' by perpetuating a kind of living environment that [is] significantly different from that which people generally experienced earlier in their lives' (Fisk, 1999:36).

In light of the growing criticisms of sheltered housing there have been calls to re-evaluate its role and function in meeting the housing needs of an ageing population. The Audit Commission report 'Home Alone' (Audit Commission, 1988) raised the pertinent issue of tying support services to housing.

> 'The principle of community care makes it harder to justify tying resources to property rather people. Sheltered housing must accordingly re-invent itself as provision for older people who prefer the presence of a supportive community, or it must re-think the levels of need it is able to support. If it does not it will face serious questions about its high levels of support in ordinary housing' (Audit Commission,1988:39).

The Audit Commission report confirms the absence of people with disabilities from discussions and the literature on sheltered housing. Yet this study demonstrates that there is a need to research and address sheltered housing in relation to the potential conflicts and tension between older people and people with disabilities, if the latter are to be accommodated in such housing. The benefits accruing to people with disabilities living in sheltered housing appear to be different from those of older people. People with disabilities are attracted to sheltered housing for the physical proximity of the available support services. Older people move to sheltered housing to be in close proximity with other older

people and place-based social activities, and not necessarily for the on-site warden services (Fisk, 1999). It thus seems that the housing literature that critiques the institutional nature of sheltered housing, for being a community under surveillance, reflects predominantly the experiences of older people rather than those of people with disabilities. The services that are perceived as less important by older people are the very ones that act as a magnet to people with disabilities and signal the potential of an independent life (ie on-site warden). There is presently a dearth of information on the experiences of people with disabilities living in sheltered housing which needs to be addressed in any discussions concerning the re-evaluation of this type of housing.

RE-EVALUATING SHELTERED HOUSING

Presently, sheltered housing is perceived to be stigmatising and to exacerbate the social exclusion experienced by people with disabilities. This results in many people with disabilities believing that they could not and would not live in sheltered housing. When segregated social spaces like sheltered housing are seen to be reproducing negative disabled imagery and stigma that contribute to the social exclusion of people with disabilities, it is understandable that outsiders believe that social inclusion is not going to be achieved by spatially segregating people with disabilities from mainstream society. However, by challenging sheltered housing as an enabling living environment and adopting the language of an ableist discourse, outsiders are maintaining the status quo rather than questioning present policies and practices. Throughout the UK there 'is a sense that sheltered housing has become 'fossilised' within an outmoded framework.

This has spawned a host of reports that call for dramatic change in the design of schemes' (Fisk, 1999:35, see Bartholomeou, 1999; Robson *et al.* 1997; Trotter & Phillips, 1997). Sheltered housing needs to be re-evaluated to accommodate the attributes of the present design whilst at the same time shedding images of negativity and to accommodate differences in relation to age, disability, gender, race, ethnicity and sexuality.

Table 5.1 highlights the positive and negative features of sheltered housing to emerge from this study. The table is divided into two main sections, enabling features and disabling features, these two principal sections are sub-divided into features that were experienced and those that were perceived and/or that interviewees had anticipated being associated with sheltered housing.

Table 5.1 Re-evaluating Sheltered Housing

Enabling Features	**Disabling Features**
Experienced • Physical proximity of warden • Security • Independence	*Experienced* • Socially constructed space for older people • Social exclusion • Physical barriers
Perceived/Anticipated • Communal lounge • Social interaction • Companionship	*Perceived/Anticipated* • Segregation • Stigma • Surveillance • Dependence

As society constructs the social dynamics of the spaces we inhabit the negative imagery applied to sheltered housing can and should be deconstructed and reconstructed more positively. There are a variety of approaches that could be adopted to achieve change. First, diminishing the physical distance between disabled housing and mainstream housing. That is the construction and location of sheltered housing that is not spatially segregated from but integrated into,

mainstream housing, thereby largely eliminating the visual cues of spatial difference and thus stigma. Not all sheltered housing schemes are spatially segregated or physically different from mainstream housing and there are extant examples of such integration. In Dundee rows of tenement flats have been renovated and transformed inconspicuously into sheltered housing. In these flats the unique features of sheltered housing that are appreciated by insiders exist without the stigma perceived by outsiders. This form of housing could be crucial in meeting the holistic housing needs of people with disabilities in the future.

> *Susan: How do you feel about living in sheltered housing?*
> *Beverley: I took bad at first.*
> *Susan: Was that because you thought it would be mainly older people?*
> *Beverley: Yeah, I would never have went to live in a closed complex, I don't think I would have been able to handle that, because as I say I've brought six of a family up, and you're dependent. I'd rather have my independence, my own front door and that's it. This is just a normal street, you can't tell it's sheltered. But I have the cords, the warden's good, I mean if I'm really bad, he phones, 'Are you needing anything, will I come along and make you a cup of tea?' They're really good, and that's not their job, they dunna have to do that, they are good.*
>
> Beverley, interviewed 18/2/97

Secondly, smart home technology may hold the key to breaking the chain between tying housing to particular types of support. It could open up new possibilities of meeting the housing needs of people with disabilities for support and security outwith a spatially defined area. However, a caveat is required here to ensure that increased technology does not diminish spatial or temporal proximity to an individual's source of support, such as a warden or place based social networks. Thirdly, a number of outsiders lived within small clusters of purpose built wheelchair houses, that were not warden linked, but were integrated into streets of otherwise mainstream housing. The people living in

this type of housing reported experiencing positive social interaction with their disabled and able-bodied neighbours. Even people who dismissed the concept of sheltered housing thought a small-scale alternative would be more successful. As Kevin says,

> *I find if you get three in a block of say 60 houses, I find that works a lot better, than your sheltered housing, because for me, sheltered housing has the stigma attached to it.*
>
> Kevin, interviewed 2/4/97

CONCLUSION

The perceptions of people with disabilities of sheltered housing were mixed. This illustrates that differences within the social group of people with disabilities can first, lead to a variety of interpretations and experiences of place. Secondly, it exposes how different social groups endow places and spaces with a range of different meanings, which can at times be conflictual, leading to the inclusion and thus exclusion of certain people, and create seemingly spatial contradictions (Sharp *et al.*, 2000).

'Socio-political contradictions are realised spatially. The contradictions of space thus make the contradictions of social relations operative. In other words, spatial contradictions 'express' conflicts between socio-political interests and forces; it is only in space that such conflicts come effectively into play, and in doing so they become contradictions of space'.

(Lefebvre, 1991:365, cited in Sharp et al., 2000:26).

Insiders' interpretations of space suggested that they wanted to be a part of their local community through participating in place-based social activities, and they

did not problematise the spatial separation of sheltered housing from mainstream housing nor its associated negative imagery. As Helen stressed to me, her experience of feeling socially isolated in sheltered housing had taught her to prioritise the social make-up and ages of future neighbours. She felt that once she was living in sheltered housing the physical appearance and associated cultural perceptions of buildings were not as important as the social composition of the people inside the buildings. Helen's philosophy is a conflation of an acceptance and tolerance of difference, which also demonstrates that the underlying concept of sheltered housing is favoured by insiders, but not in its present form. The message received from insiders is that they value the linked warden alarm system for the greater sense of independence, security and ability to live on one's own that this feature conveys. However, insiders are being excluded from participating fully in communal activities because sheltered housing appears to be constructed and functions to meet the needs of older people and not a heterogeneous mix of ages. Thus, whilst 93% of insiders wanted to move house, this same group of people would be interested in remaining in sheltered housing if they could feel integrated, included and a part of their community.

In contrast, outsiders could not conceive of themselves living in sheltered housing. The very mention of it conjured up ideas and images of stigma, dependency and surveillance. Outsiders identified with or sought to identify with the able-bodied majority and living in integrated housing helped them assimilate that assumed identity and feel 'normal'. Thus, outsiders perceived socially

constructed, imaginary boundaries between themselves and the spaces insiders occupied.

When the experiences of insiders and outsiders were compared place and perceptions of place appeared to be critical in influencing the way individuals negotiate their identity and the type of housing they wanted to live in. Insiders were ready to acknowledge their difference from a culturally defined normal body, and attempted to draw strength from that by socialising and identifying with other people with disabilities. Whereas, despite some outsiders trying to disregard their differences in an able-bodied culture, their perceptions appeared to reflect a social discourse that equated the physically impaired body with being negatively different. The spatial contingency of insiders and outsiders knowledge and the negotiation of their identities highlights the way disability and stigma are socially constructed. Recognition by policy makers and society at large of the socio-spatial and temporal nature of the concepts of stigma and disability should herald an important step on the road to questioning, challenging and changing present ableist values and practices.

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[1] This is not to overlook the fact that a large number of older people are physically impaired and 40% of the over 65s use a wheelchair (Cope, 1999). Throughout this thesis reference to people with disabilities specifically refers to the under 65s unless stated otherwise.

[2] For non-sheltered housing the community alarm system is linked to a local control centre that would contact an informal carer if necessary (ie family member, friend or neighbour) or a if necessary a formal carer (ie social care officer) to assist the person who made the call for help. When registering for a community alarm each individual must provide the name and address of a family member, friend or neighbour who could be contacted in an emergency as a key holder, someone who could gain access to the individual's house.

[3] In addition the communal lounge was intended to make up for the smaller space within sheltered houses. Circular 82/69 set space standards of 33m^2 for one-person bedsits and 48 m^2 for two-person, one bedroom units (Cope 1999).

[4] In addition to age, it is probable that the majority of older people in sheltered housing are white, Christian and largely able-bodied (although perhaps frail). Although no data was collected in this study to confirm this, other research has highlighted the under-representation of black and ethnic older people in sheltered housing, and the inappropriateness of such housing for these people (see

Jones, 1994, 1998). This suggests there is scope for further research to investigate the suggestion that sheltered housing is principally constructed for an ageing white, able-bodied, heterosexual man/woman.

[5] A summary report (Levy, 2000, see Appendix E) of some of the findings of this study has been forwarded to service providers in an attempt to raise awareness of flaws and weaknesses in Dundee's present housing practices with regard to people with disabilities.

[6] Issues relating to degrees of disability and looking 'more' or 'less' disabled are developed in Chapter 7. In the example here of Liz and Penny part of the explanation for them being excluded from the arthritis meeting was due to their age (and arthritis being understood within prevailing social discourses to affect older people). In addition neither woman looked very 'disabled' when they attended their meetings, they were going through a 'good patch'. In other words despite the pain and discomfort that is a part of their every day lives and leads to their exclusion and marginalisation they couldn't convince the gatekeepers that they had arthritis.

[7] This study can not confirm people with disabilities were excluded from communal lounges and 'arthritic space' based on their age, but age certainly was a contributing factor to the exclusionary process. Looking at these findings from an older persons perspective, would I assume, be quite empowering when the prevailing social discourse suggests that older people are marginalised and oppressed within society through a discourse of ageism.

[8] Although insiders did not associate sheltered housing with stigma, their experiences suggest that some of them were subjected to unstated, implicit stigma by the older people.

[9] Megan is referring to sheltered housing where it is common practice for tenants to notify their warden that they are up and well each morning by wheeling over a mat that has a link underneath it to their warden.

[10] It should be noted that there was a general reluctance amongst many outsiders for formal carers to enter into the private spaces of their home, either physically coming into their home, remotely through an alarm system or psychologically through keeping an eye on their daily movements.

6

EMPOWERMENT AND SOCIAL INCLUSION:

UTILISING KNOWLEDGE AND CHOICE

INTRODUCTION

During the 1990s the concept of social exclusion, which emanated from the work of French sociologists in the 1970s, spread from the continent into British politics and social science research. Social exclusion introduced a new dimension into theorising social deprivation and marginalisation by conceiving of these issues from a more holistic perspective. Interest shifted from purely economic and structural explanations of social isolation and deprivation, to encompass complementary cultural explanations. This new approach, relates to the denial of social citizenship status to certain social groups, based on stigma, oppressive legislation and segregation from and within society (Somerville, 1998). Madanipour (1998) argues it 'largely revolves around access. It is access to decision making, access to resources and access to common narratives' (p.80). In the previous chapters, structural and cultural explanations of social exclusion, framed in the social model of disability, have been used to address the barriers experienced by people with disabilities in relation to the design and segregation of housing, and place-based social interaction of people with disabilities. This chapter extends the discussion on social exclusion and barriers to inclusion into a less tangible but equally significant area of concern: that of

empowerment, and specifically, the access people with disabilities have to housing information and their ability to exercise choice and control over their housing outcomes.

> 'Housing processes can be understood as types of processes which either promote social inclusion or contribute to social exclusion. Social exclusion through housing happens if the effect of housing processes is to deny certain social groups control over their lives, or to impair enjoyment of wider citizenship rights'.
>
> (Somerville, 1998:772).

At the start of the twenty-first century we live in an information rich society, in which more and more information is available to us from an increasing range of sources. How information is made available to people and how it is interpreted is largely dependent on prevailing power relations. Consequently not everyone is included, there is an unevenness between various sections of society in terms of accessing and influencing information and the knowledge it generates. People with disabilities, as service users, are one group of people who are, to varying degrees, excluded from participating in this process of constructing knowledge. Yet knowledge is a potential source of power that both service users as well as service providers have. However, to date the former have been prevented, and thus disempowered, from utilising their acquired and experiential knowledge.

> The dominant experience of disabled people when they place themselves in the hands of professionals is one of knowledge denial rather than knowledge enhancement (Laws, 1994; Dyck, 1995, 1998; Imrie, 1996a) as their ways of knowing and accounting for their experience are devalued as insufficiently 'dispassionate' and 'objective'. All too many programs and services for the disabled presume passivity on the part of the consumer – a blank slate upon which institutional protocols are inscribed.
>
> (Dorn, 1998:198).

Scottish Homes have acknowledged in their Care in the Community Policy Statement (1998) the importance of empowering service users. 'The guiding principle of our Policy reflects our wish to enable people with particular needs to have control in their housing environment' (Scottish Homes, 1998:4). It is the relationships between choice and control, in relation to knowledge and power that are the focus of this chapter that is divided into three principal sections. The first section entitled, 'Second Hand Knowledge' explores the accessibility of relevant housing information to service users, particularly via service providers. The second section addresses 'First Hand Knowledge', that is knowledge gained through everyday experiences of embodiment and living in different spaces and places. It looks at the power interviewees have to draw on their housing experiences and knowledge of their housing needs to exercise choice and control over housing decisions. The third and final section draws the previous two together to illustrate that (in)voluntary intra-urban migration is one of the consequences of restricted acquisition to and utilisation of knowledge, coupled with an inadequate supply of suitable housing, that can position people with disabilities on the margins of Scottish society.

SECOND HAND KNOWLEDGE

> 'Scotland contains many different communities with different needs, varying age and ethnic groups and social catchments, people who are differently abled. Provision of advice and information in housing has therefore become a complex business. How do we get information to all these communities in a way that is relevant to them?'
>
> (Homepoint, 2000:2).

The question of how to ensure people have access to relevant and timely information is emerging as a central concern of housing practitioners in Scotland. At the Homepoint/CoSLA 2000 Conference, Goodlad spoke of 'Mainstreaming Information and Advice' (Homepoint, 2000:3) to make information accessible, to make sure people know where to find it, so that providing information becomes a part of the normal, mainstream way of working for housing practitioners. Scottish Homes have been encouraging housing providers for a number of years now to engage more directly with communicating information to and listening to their clients. In its 1998 Care in the Community Action Plan, Scottish Homes set a target of 2001 for people with disabilities to have improved access to good information and advice on housing related issues (Scottish Homes, 1998). The Action Plan states that '[e]asily accessible advice and information on housing options is essential to ensuring the provision of appropriate housing for all' (Scottish Homes, 1998:24). The need for the proposals laid out in the Action Plan are borne out by research (see Disability Scotland, 1994; Scottish Homes, 1995b; MacFarlane & Laurie, 1996) that indicates that effective communication and access to relevant information remains elusive and unattainable for many people with disabilities.

Accessing Information from Service Providers

Many interviewees in my study felt 'information poor' and were keen to know more about what they were entitled to, with regard to housing, care services, or adaptations and aids. They were also unsure of where to go or who to ask for information. The following examples illustrate these points. First, during

Maureen's interview we talked about accessible design features, including lowered work surfaces in the kitchen. Maureen had neither seen nor heard of an accessible kitchen but could imagine how useful it would be for her to work facing a work surface with her legs underneath it, rather than having to work sideways. A few weeks after I had interviewed Maureen she phoned me to ask who she should contact about having the work surfaces in her kitchen lowered, since no-one else had talked to her about it and she didn't know who would be responsible for dealing with such matters. Secondly, many interviewees, who did not have a community alarm, knew nothing about the service, but they were interested in acquiring more information about the alarm.

Susan: What about the community alarm did you ever think about taking that, or has anyone ever discussed it with you?
Alex: No, no-one has, what is it?
Susan: It is an alarm that you activate yourself if you need help by pushing a button on a pendant worn around your neck, or by pulling on a long cord hanging from the ceiling. The alarm is connected to a central office who contact someone to come and help you.
Alex: No, I haven't heard of that, you mean to say if I was lying half dead on the floor, someone would come to help?
Susan: Yes.
Alex: I need to talk to my social worker about that.
Judy: It would be good to know that it was there.

Alex interviewed with her sister Judy, 11/4/97

These examples suggest that service users are not receiving adequate information on housing and available services from housing and social work practitioners. This may be a result of economic constraints and service providers realising that they are unable to provide everything that a client may need, and hence they are cautious with the information they pass on. Alternatively, ineffective communication between different agencies (health, social work and housing), where each agency is unaware of what the others are doing and saying, may be

prohibiting relevant information being conveyed to service users. Whatever the explanation, service users are not being fully informed of the services that are available to them. Without this information they are unable to make informed choices about what they need and want, and are thus unable to ask service providers pertinent questions about products or services they could benefit from. As Gail and Zoe remarked:

> *Nobody'll tell you what you can get, you have to shout and shout loudly at the right person, until you get something, and it's wrong, it's so wrong.*
> Gail, interviewed 30/1/97

> *When you come home (from hospital) and ask what can I have, they don't tell you. You have to tell them what you need and they'll see if you can have it. It's not the case of what can I have and here it is.*
> Zoe, interviewed 8/12/96

Gail and Zoe are both owner occupiers, but across all tenancies interviewees were experiencing difficulties in either accessing information regarding the adaptation of their house or information on finding and moving to a suitable house. However, the over 55s and interviewees living in social housing appeared to be encountering the greatest difficulties finding relevant housing information. Seventy-nine per cent of the over 55s and 69% of all social housing tenants found it 'difficult' or 'very difficult' to access housing information, compared to 33% of 16-24 year olds, and 32% of owner occupiers. Yet, it should be noted, that none of the interviewees found it 'very easy' to find relevant housing information (Figure 6.1).

Figure 6.1 Ease with which interviewees were able to access housing information by tenancy

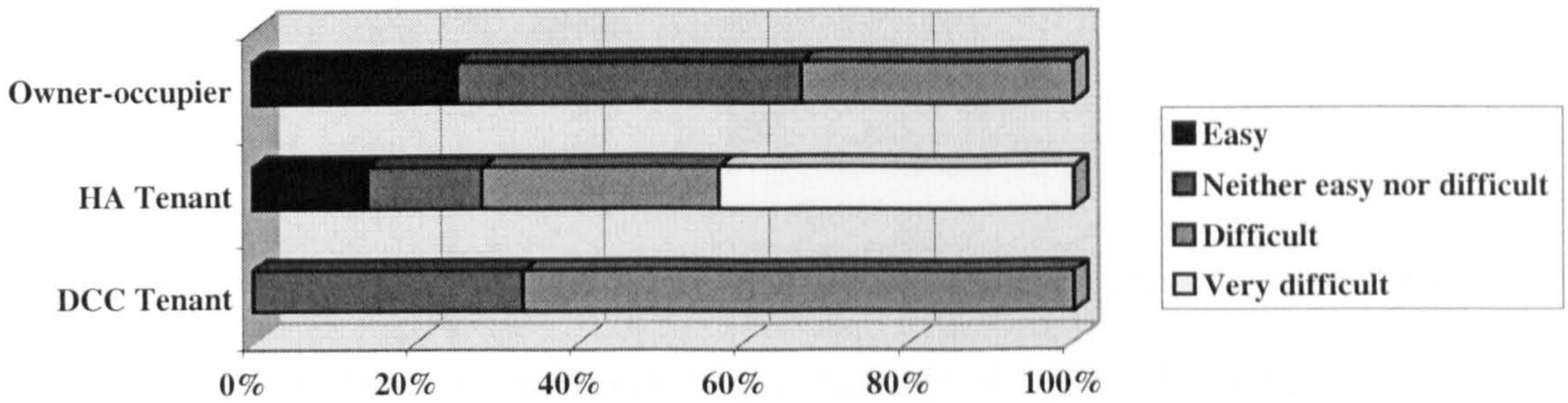
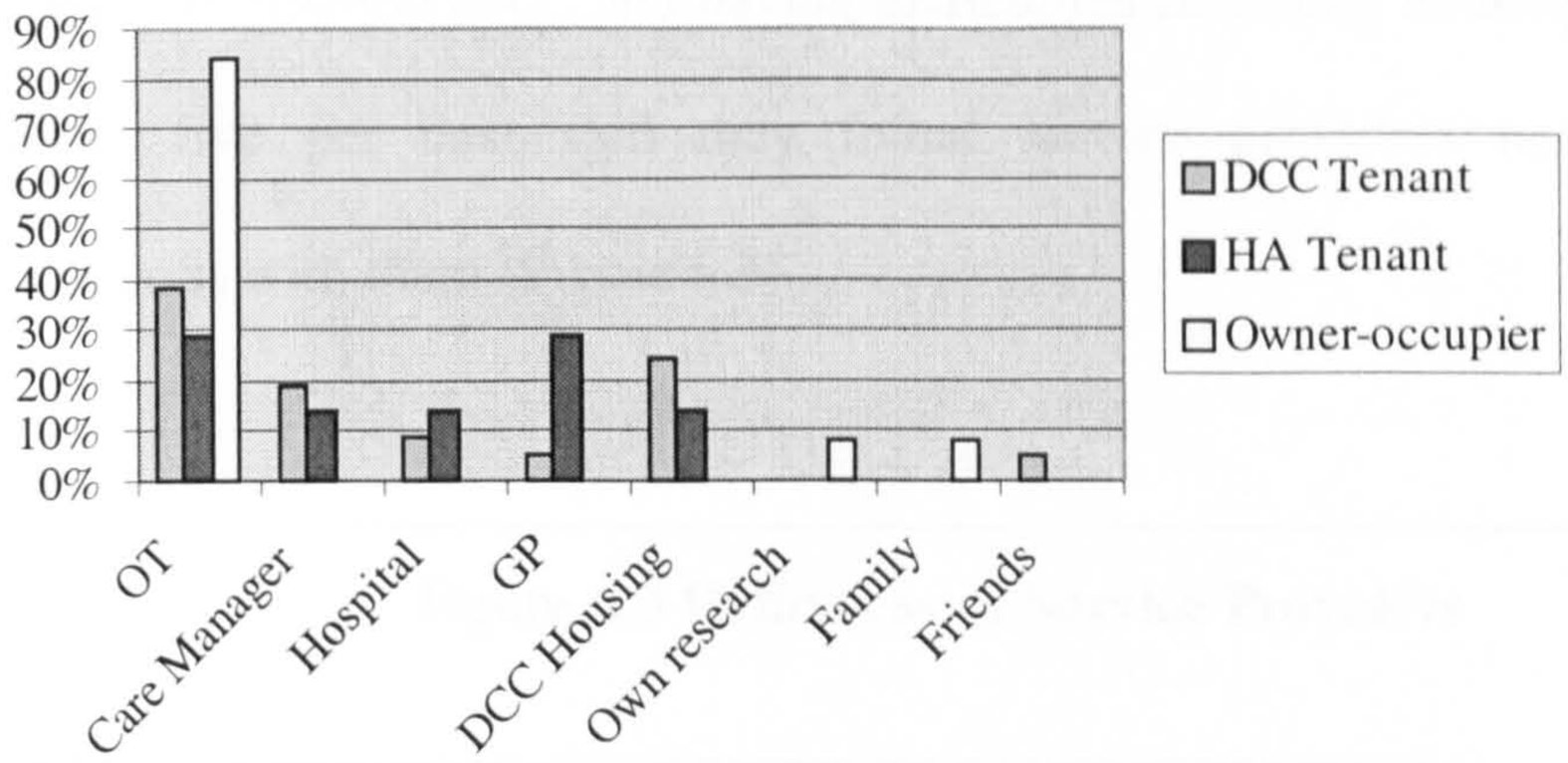


Figure 6.2 Sources of Second Hand Information by Tenancy

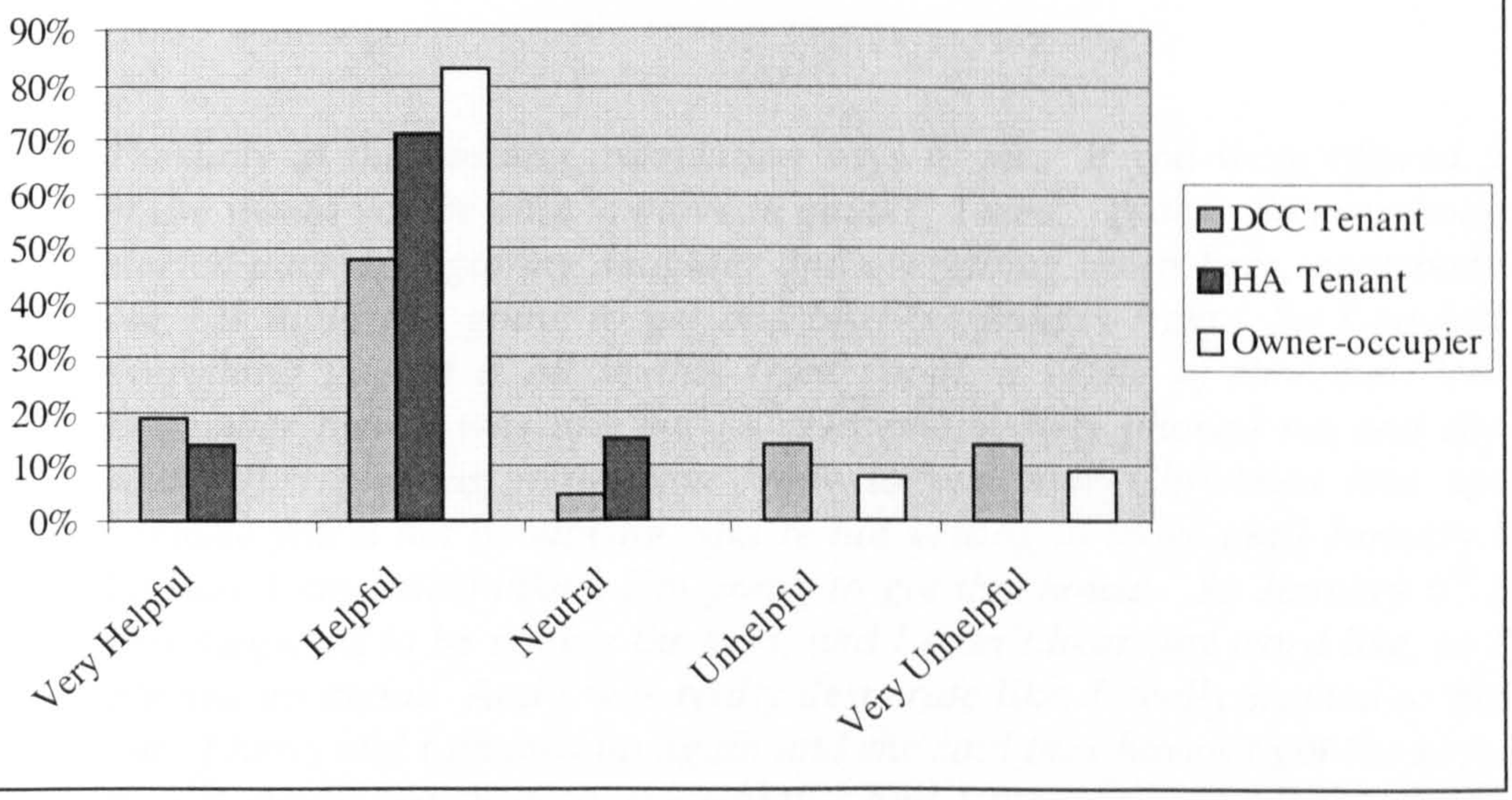


Only one interviewee said her primary source of housing information was derived from her own research using magazines or the Internet where she found details of design developments and services for people with disabilities. The rest of the interviewees had been dependent on service providers as their primary source of information (Figure 6.2). For most interviewees, occupational therapists were the most likely sources of help and advice: 58% of interviewees had more contact with occupational therapists than with any other service provider. This was particularly true for owner occupiers who used occupational

therapists more than any other group. Sheltered housing tenants were, however, more likely to have received information about housing options from health professionals (GP's and hospitals) rather than from housing or social work practitioners.

Overall, service providers appeared to be crucial in passing information on to people with disabilities. As such service providers play a pivotal role in ensuring their clients have access to or know how to access relevant information about housing and services for people with disabilities. A good working relationship between providers and users is therefore paramount. Despite many interviewees feeling 'information poor' and having difficulties accessing housing information, seventy five per cent said they found service providers helpful in their interactions with them (Figure 6.3).

Figure 6.3 Helfulness of Service Providers



The findings summarised in Figure 6.3 should not however make service providers complacent for two principal reasons. First, these findings are drawn from a small data set, and secondly, the positive results should not overshadow the negative ones. For it is the latter that hides the real areas of concern, of why people are dissatisfied with the service they are receiving and how things can be improved. Many of the interviewees who were unhappy with their interactions with service providers were living in unsuitable and distressing housing situations. Thirty three per cent of interviewees living in mainstream, unadapted housing felt service providers were 'very unhelpful'. This suggests that interviewees' present housing situation may be influencing their perception of their interactions with service providers. Living in housing that is unsuitable and disabling can be distressing and frustrating, especially if one feels that the people who are in a position to influence their housing do not appear to be doing anything to rectify the situation. As Penny explains she feels service providers are letting her down rather than genuinely seeking a solution to her housing needs.

> *The lady at the housing association says to me, 'If you were offered a house would you be able to move in quick?' I said, 'Yeah'. So everybody started packing I got my daughter and everything down here, everybody coz I thought I'm going to get one of these houses right. So I packed everything up put it all in this front room, a waste of time but, 'eh. December then it was like the 13th December, they phoned me and she said, 'Just phoning to let you know to put your Christmas tree up, because you'll not be moving, you're not getting to move until January.' So here I am still thinking I'm going to get this house. So January 6th I was supposed to be getting the keys, and I didn't hear any word like, so I phoned up again. And I was really desperate like, I really wanted to get out of here, and I phoned up again and she said they haven't got the keys, they'll maybe get them on the eighth. And I thought so, well the eighth went by, and I phoned up, and she said I wasn't getting the house. So it was a big, big disappointment, I was in tears, I thought ken how can they do this to me, and I just thought this is really just hopeless.*
>
> Penny, interviewed 5/2/97

Similar stories to Penny's were recounted by other interviewees and in each case the interviewee had to make phone calls to receive an update on their imminent move. As Helen points out, there is still much work to be done to improve interaction and communication, and to open up a reciprocal dialogue between service users and service providers. She succinctly captures the essence of one of the principal barriers that prevents service providers communicating effectively with people with disabilities and that is, seeing them as 'people'.

> *Susan: What about communication between you and the housing department, do you think that could be improved?*
> *Helen: Yeah, but I think it would take a long time, you've first of all got to break down the barriers and make them realise that you're not just a name on a piece on paper, you're a person. And you've got to make improvements in social contact, when I phone up, because I've got a speech impediment my voice will eventually start to get quieter and quieter, and I think they think I'm not fully compos mentis, when they could be more patient.*
>
> Helen, interviewed 6/2/97

Tackling the ingrained negative perceptions that service providers appear to have of people with disabilities is a fundamental requirement, yet altering established cultural norms is a lengthy procedure. Working towards attainable short-term goals could potentially reduce the number of unsuccessful moves that are made by people with disabilities. Two possible approaches that could be adopted to achieve this objective, that were alluded to by interviewees, are first, broadening the information service providers offer their clients. This could include socio-demographic information about the neighbourhood, in addition to information about the accessibility and location of shops, doctor surgeries and other local amenities. Secondly, service providers could allow more time for their clients to visit a house and offer the choice of additional visits if their clients felt they

needed to return to view a house for a second or third time. In the private sector interested buyers have the freedom and choice to spend time viewing houses they are interested in, social housing tenants should feel under no more pressure to make a rushed or uninformed decision on a house than potential buyers do. Yet the present system of social housing, especially with regard to a limited stock of special needs housing, appears to be putting people under undue pressure to accept 'whatever' is offered to them, even if the house only meets their medical needs and not their social needs. If more information and greater control was passed on to service users, a move to a new house that may exacerbate people's feelings of being socially excluded could potentially be prevented. Helen, for instance, is unlikely to have moved to her present flat in a sheltered housing scheme had she had access to more information about the neighbourhood and the type of housing she was moving into.[1] When I met Helen she was extremely disappointed and depressed by her recent move. She felt isolated and lonely surrounded by older people, and she felt let down and annoyed by the failure of service providers to inform her about the reality of living in sheltered housing.

Helen: There is one thing I really disagree with, that's social workers, or OTs and the wardens. When I first came here ... I admit I thought it was the right move, and from April to November no-one said anything. I thought OTs and social welfare are bound to have the information and I'm quite sure if they thought a bit more laterally they could think about how they would feel if they were in my situation. But I get the feeling that you're just a name to them and when they get you allocated that's their job over and done with.

...

Susan: Did you come and see the house before you moved in?

Helen: Oh they showed me it, but the day I came with mum and dad, the girl from the housing came and twenty minutes later a taxi came and she was more concerned about getting away to her office than explaining to me about the house and I felt a bit hurried. She kept saying, 'Come on, come on my taxi is here'. And now looking back, dad wished he had offered to take her back to her office, because he realises that I hadn't had long enough to really think

> *about the house. ... Everyone's got different needs and they don't take them into account and they don't even try to put themselves in the situation.*
>
> Helen, interviewed 6/2/97

Scottish Homes have identified access to information as a key priority that they are addressing through their Homepoint publications. These short guides aim to 'improve the scope and quality of housing information and advice throughout Scotland' (Scottish Homes, 1999a)[2]. The recently revised 1995 'Access to Housing in Scotland, Rights for Disabled People' (Scottish Homes, 1999a) is a comprehensive guide to assist people with disabilities to find a suitable house or adapt their home. Although interviewees were not specifically asked if they had received this Homepoint publication, there was no evidence to suggest that they had access to this or other publicly available guides.

An alternative strategy that has been adopted to tackle the problems encountered by people with disabilities in accessing relevant housing information has been the development of a 'one-stop shop' for housing information. The Walbrook Housing Association in Derby pioneered the idea of placing all housing information in a single location. The housing service offers general housing advice, advice on aids to mobility, estimates of housing costs and financial advice, information on renting or purchase of accommodation, the provision of individually adapted housing and counselling (JRF, 1990). There are similar Disabled Person's Housing Services in Sheffield and Lothian, and, based on the findings from this study, there appears to be scope for developing a one-stop centre in Dundee to meet wheelchair users needs for easier access to housing information.

FIRST HAND KNOWLEDGE

People with disabilities have a wealth of information about their housing needs gleaned from their first hand experience of living in and through a physically impaired body. This information is different from that available as second hand knowledge from service providers, for example, the availability of accessible houses or aids and services. First hand knowledge is derived from experience, for example, from what it means, if you're physically impaired, to live in a (un)suitable house, whether a certain design or location of house or service is meeting your needs. Service providers are in a position to capitalise on their clients' first hand knowledge to improve the service they offer, yet to date the balance of power has been weighted against service users. As a means of reversing such practices Scottish Homes (1998) have called for their strategic partners to recognise and establish the process of consulting and listening to service users. This requires a change in working practices to recognise that people with disabilities are a source of knowledge. The challenge for service providers lies in reconfiguring the hierarchical power relations between 'us' and 'them', to establish a bottom up flow of information from service users to service providers (first hand knowledge), to complement the top down flow of information from service providers to service users (second hand knowledge).

When Ben said, 'they're not building houses for people, they don't listen to us' (interviewed, 9/1/97), he succinctly captures one of the critiques of modernist design. That is, it failed to communicate with or engage with the subjective experiences of the users of the built environment (Imrie, 1996a). Many

interviewees recognised the value of service providers talking to people with disabilities as a channel for accessing first hand knowledge, and were disappointed that this channel of communication was under-utilised.

> *Iris: ... it's like research they're not taking the benefits of what other people have done to help the disabled. So they're starting up with attitudes and ideas and each generation has to get that knocked out of them until understanding is developed before it will actually take on. Even the councils and that are still not aware of what they're doing wrong.*
> *Susan: What do you see as the best way of moving forward?*
> *Iris: I think a lot more consultation with disabled people, and really just 'em people like yourself, people at the ground you know when you're starting out taking an interest in how they can help, before they go and make mistakes and learn by their mistakes. A lot of people from the department learn from their mistakes, and say "Oh if only we'd known".*
>
> Iris, interviewed 28/1/97

In the following sections I consider the power people with disabilities have to exercise their first hand knowledge, at the scales of the home and the neighbourhood. More specifically, in relation to formal care within the interviewees' home, influencing decisions about the design and location of their home, and finally, exercising control and choice over moving house.

Formal Carers in Private Space

There is a growing geographical literature on the home as a caring space that is beginning to look at the role of formal carers (McKeever and England, 2001; Wiles, 2001). This literature has problematised the traditional boundaries between private and public space through blurring the boundary where private and public space meet. Formal carers are partly responsible for disrupting this fragile dualism between private and public space[3].

Many people with disabilities require assistance and help with personal hygiene and with running a household. NHS nurses or nurses from voluntary organisations such as Crossroads make regular visits to help people with getting up, showering and going to bed. Whilst the interviewees who received nursing care realised they were unable to remain in their home without it, they often felt that the nurses were invading the private spaces of their home to perform intimate and personal caring tasks. In particular, some interviewees felt that they were unable to develop a trusting and understanding relationship with their formal carers. This was largely due to there being little consistency in the personnel who cared for them or the times that nurses arrived at people's home. This led to people feeling uncomfortable and often embarrassed in their own home.

> *Anna: It's like the nurse who come in this morning from Crossroads, I've seen her once, she come in this morning, she never opened her mouth. She just said, 'Yeah you're wanting your hair washed', 'Yeah'. So I had to keep speaking to make conversation.*
> *Betty: Whereas the nurse that come in yesterday, was saying, 'And how are you today Anna.' Now what a difference that makes if someone speaks to you it makes you at ease.*
>
> Anna, interviewed with her mother 31/1/97

Home helps also come under the umbrella term of formal carers. They assist people with cleaning, cooking and are available to help out generally in the home. However, many interviewees stated they would have preferred to have managed these domestic duties themselves rather than having someone 'poking their nose into their business'.[4] Concerns were raised with regard to privacy in relation to home helps, and the cost of paying for one, but the main criticism of home helps was that interviewees felt they had little control over what they did to help them.

Like I had a home help, but I had to stop it. The whole idea of a home help is that she comes to help you, and she used to sit and drink a cup of coffee, she used to really leave me with more hassle than help. She tidied up the kitchen, but tidied up things out of my reach, so I couldn't get them back down again. I explained to her what I wanted. But the one I've got now is very good, she'll put things back where I can reach them.

Iris, interviewed 28/1/97

Now this person come up at night and said we're the home help, we're here to cook your meal. Forty-five minutes a night to do housework and cook your meal. Then they decided they didn't do housework, and they weren't allowed to use certain things and do dishes, so they come for 45 minutes, by the time they'd peeled the potatoes I mean there was nobody to cook it anyway. So I think social works, maybe they're fighting a budget like, but they only give you what they think is necessary, they'll give you a hot meal, never mind if you're needing anything ironed, washed or cleaned or anything. So I think they just do the main thing and leave you the rest and hope you've got family, or something like that, but for some folks it must be hard.

Gillian, interviewed 12/2/97

In contrast to the experiences of Iris and Gillian, Gail had, she acknowledged, been fortunate with her home help. She had had the same home help for a number of years during which time the two women had developed a trusting and honest relationship which meant that Gail could tell her home help exactly what she wanted to be done or if necessary criticise something the home help had done without offending her. This reflects Gail's retention of a significant amount of control generally over the running of her and husband's home. For example, she explained to her husband what and how to cook or clean, yet she was careful not to take advantage of the people who helped and cared for her. Gail explained how she perceived the relationship between increasing physical dependency and losing control over one's ability to determine the outcome of events had made her more tolerant and less of a perfectionist. As there is little, she said, she can do to change an unsatisfactory outcome.

You know about taking advantage, that's something you always feel, I think because you're in a chair you're not as able so you feel, or I do, I feel that I'm taking advantage of people at some point. So again you accept some things, you wouldn't have accepted ten years ago, you know because you would just get up and do it yourself. But when you can't do it yourself, you have to accept it, and it's not an easy thing to come to terms with, especially when you've been a very independent active person.

Gail, interviewed 6/2/97

What Gail was highlighting was that in certain areas of one's life, an impaired body reduces the control and power one has to influence outcomes, and these situations must be recognised and accepted. However, there are other areas of life, like requesting a nurse to come at 8am and not 7am for a morning shower, or expressing a desire to remain in the family home and not move, that are personal choices and decisions that should be left to the individual to make, as they are for the majority population who do not have to conform to the time schedules of someone else's work regime. Admittedly, service providers are working under increasing pressure to serve more clients within limited budgets, but these clients still need to be treated with respect, their first hand knowledge is valuable and they should have opportunities to use it, to be empowered to influence what happens within their home environment.

Exercising Control over Housing Decisions

Tenancy has been a defining variable in the housing literature on social exclusion, with the owner occupied sector being perceived as the inclusive sector, symbolising economic security and normality (Marcuse, 1975). The social housing sector has traditionally been perceived as the antithesis. Recent

studies have shed a different light on this latter tenancy group suggesting that as a housing sector, social housing is not necessarily synonymous with social exclusion (Harloe, 1995, cited in Somerville, 1998) and unhealthy housing (Easterlow, *et al.*, 2000; Smith *et al.*, 1998). These studies indicate that social housing tenants reap financial and health benefits from their housing, respectively. Chapter 4, seemed to confirm these findings, by illustrating that housing association tenants, more than home owners and council tenants, were living in well designed houses and receiving positive health outcomes from their housing. The following section re-examines the relationship between tenancy and social exclusion, with regard to the ability of people with disabilities to exercise choice and control over housing decisions. Here social renters are shown to be more likely to feel marginalised and disempowered, than are owner occupiers.

Social renters appeared to be particularly sensitive to feeling that they were not being listened to and had little choice, flexibility or control over their housing outcomes. As Alex testifies such issues appeared rhetorical to her.

> *... the thing is they did ask me, but they already had their minds set on what they were to be using. And they just asked me, it was just like, yes we'll let you think that you're going to get that but we're not really going to do that because we've already made up our minds. ... They just ignore disabled people and humour them.*
>
> Alex, interviewed 11/4/97

Thus, contrary to the objectives laid out by Scottish Homes (1998) and the responsibility of service providers to consult with service users in accordance with the NHS and Community Care Act 1990, interviewees expressed feelings of

disempowerment, insignificance and marginalisation in decisions governing their housing, rather than experiencing empowerment through knowledge and choice. The government recognises 'that people who become involved in managing their own housing often find it an 'including' experience in itself, and are then able to build on that experience to participate more widely in community life' (Scottish Office, 1999a). The Scottish community-based housing association movement is adopting this philosophy as it seeks to empower local people through involving them in decisions influencing their housing. To this end, in the early 1990s Dundee City Council, innovatively and successfully, consulted a handful of prospective disabled tenants before building individualised houses for these people. The tenants that I spoke to, that had been involved in this scheme, felt they had been empowered, included, and their opinions valued. Housing planners and architects had listened to the needs of future tenants and put their suggestions into practice. As Gillian suggests, she felt that her first hand knowledge had been valued which had empowered her to make informed choices about the design of her house. Gillian illustrates that choice and control act as a litmus test for the accessibility and utilisation of knowledge and power, for without them one can not exercise choice and control.

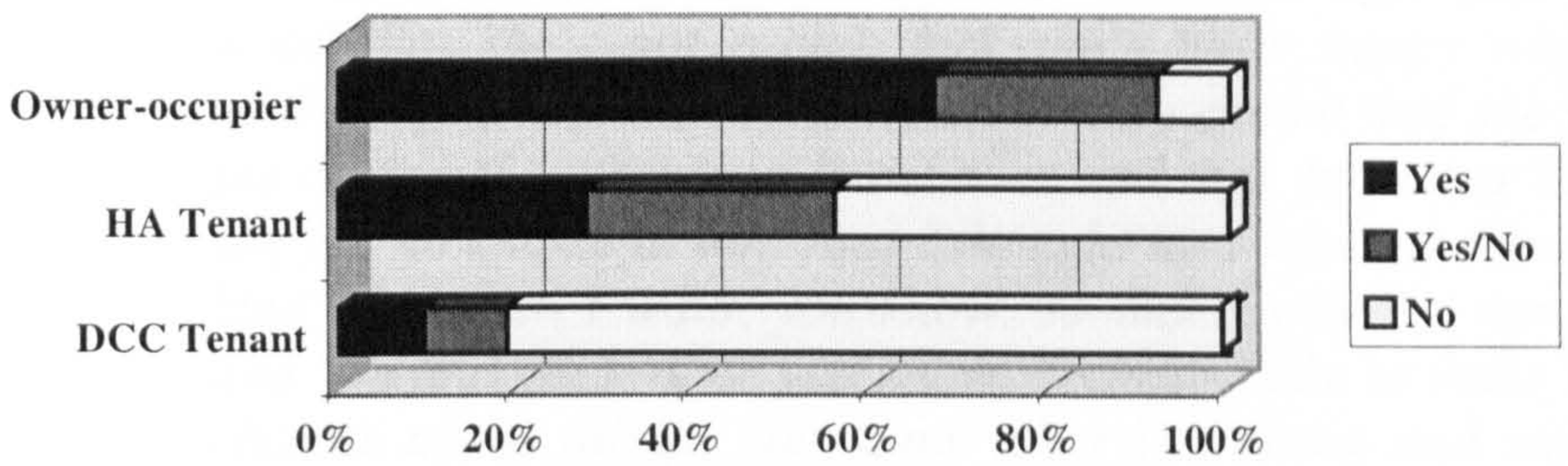
> *[This house] it's been our saving. They asked us, 'em they got five people with different disabilities, and asked us what we wanted and then they built them. ... there wasn't any plans, they come and seen all of us first like, when we were in other houses like and asked us what we wanted, how many rooms, where would you like your cooker and things like that. And then they built them. ... It's better than anywhere else coz we were asked what we wanted, which is important.*
>
> Gillian, interviewed 12/2/97

Despite the success of this venture by Dundee City Council, Gillian doubts whether the council will repeat the exercise because of financial constraints.

Hence, she questioned Dundee Council's sincerity in complying with their responsibility to consult with and listen to service users, as she understood they are required to do, under the NHS and Community Care Act 1990. It appeared that Gillian and other local authority tenants who were involved in Dundee Council's innovative, consultative scheme were 'lucky'. For other social housing tenants the scenario is very different with regard to their involvement in decisions governing their home (Figure 6.4).

The findings summarised in Figure 6.4 point to the disparity between owner occupiers' involvement in decisions influencing their house and social housing tenants' involvement. For social housing tenants the barriers of a hierarchical relationship between 'us' (service providers) and 'them' (service users) are leaving them feeling like they are not being listened to, and that they are unable to communicate effectively with service providers.

Figure 6.4 Interviewees who felt they were involved in housing decisions by tenancy



Penny suggested that the limited choice she had with regard to her housing was a consequence of her being disabled. In doing so, she demonstrated the pervasiveness of an ableist discourse and its power to percolate into the thinking

and embodiment of people with disabilities as 'internalised ableism' (Kitchin, 2000:34).

> *I remember I was down at the office (DCC Housing Dept.) and they'd put Ardler or something down and I says, I never asked for that. And they says, you can't have it otherwise, you've got no choice. Because it's disabled you've not got any choice. And so really it's your life, if you're disabled, you've not got any choices, you canna decide what you want, and you've just got to put up with what everybody else wants.*
>
> Penny, interviewed 5/2/97

The tension between the control and choice that social housing tenants are (un)able to exercise with regard to housing decisions, compared to owner occupiers is captured in Gail's involvement in the adaptation of her home. She felt in control of the situation and her interactions with service providers. As Gail said, 'I was able to make my ideas known'. Sara is equally aware of the privilege and power her owner occupied status gave her to make decisions about her housing.

> *Sara: Well that was one of the things, 'em that we decided, because from what I'd already heard, from me mum (in social housing), you didn't get a decision, you didn't get a choice of colours you wanted in the kitchen, my mum's OK it's that light pine type of wood that she's got round, that she's quite happy with. But neither did she get a choice, 'em the only choice that she got was the choice of cooker, you know oven and that, but other than that she got no choice at all. And I thought no I want to choose what kind of kitchen I want, you know, so that's why we went ahead and 'em and got it done you know, because I like to make my own choices about things, you know what I'm doing and where it's going to be done and that.*
>
> *Susan: Are you saying that if the council's involved you don't have that choice?*
>
> *Sara: You don't not really, they have their set people, as to who they go to, and for kitchens its somebody in the Ferry, for stair-lifts and bathrooms, it's Glasgow, you know.*
>
> Sara, interviewed 25/3/97

The experiences of interviewees' demonstrates that there is a long way to go to eliminate the disparities in the housing experiences of people with disabilities, primarily based on tenure. To diminish this disparity service providers need to facilitate the expression of housing needs by social housing tenants and to incorporate these needs into housing practice. People are unlikely to feel included in the society in which they live, if that society makes them feel devalued, insignificant and silences their voices. Facilitating the exercise of choice and control by people with disabilities over issues affecting their housing enables them to use their first hand knowledge. When this happens knowledge is converted into power: knowledge becomes empowering.

In the following section the focus of investigation shifts from looking at the individual within his/her own home, to the individual within the social setting of the neighbourhood. The role of location is addressed through an examination of interviewees' experiences of social inclusion, independence and control over their use of public space. In Chapter 5 discussion on NIMBYism illustrated how first hand knowledge can challenge the stereotyping and negative imagery of people with disabilities associated with ableism. That accepted norms can be challenged and changed over time and through physical proximity once people have accepted and acknowledged the normality of the everyday lives of culturally defined abject bodies. Thus, socio-spatial and temporal factors appeared to be influencing how quickly and smoothly people with disabilities were accepted and made to feel a part of their neighbourhood. This is important since an understanding of the social processes that are involved in people with disabilities being accepted into a new neighbourhood could help make housing

practitioners more sensitive to the holistic housing needs of people with disabilities, and in particular more cautious about moving people. Since an inadequate supply of special needs housing coupled with the unsuitability, for adaptation, of much of the remaining local authority housing stock (Spicker, 1993), means that many people with disabilities are forced to move house voluntarily and involuntarily. Tenancy remains an important characteristic in the following section for differentiating between the choice and control social housing tenants and owner occupiers appear to have over decisions to move house. The previous sections of this chapter are drawn together here to illustrate how second hand knowledge and first hand knowledge are useful concepts in understanding the power relations involved in decisions to move house.

THE NEIGHBOURHOOD COUNTS

Moving House or Staying Put?

For the majority of people moving house is an inevitable occurrence at some point in their lives and is usually associated with employment changes and/or life course changes. Even so moving house requires a lot of planning, and frequently results in people being uprooted from a familiar social and physical environment and exchanging security and familiarity for the unknown and unfamiliar. For people with disabilities these factors are exacerbated by the need to be aware of and responsive to the challenges posed by the physical environment, in addition to establishing a new social network. They must learn to read and predict the physical layout of their new neighbourhood: the location of dropped kerbs, steps

and accessible amenities, all of which requires time and energy. Dorn (1998) suggests that the experience people with disabilities have of dealing with problematic and disabling spaces, and their ability to learn to read new landscapes with very few visual and spatial cues shows a geographical maturity, an ability to be sensitive and responsive to changing environmental conditions. Even so moving into unknown territory is associated with people with disabilities being unable to predict and prepare for possible frictional spatial encounters and disorientation.

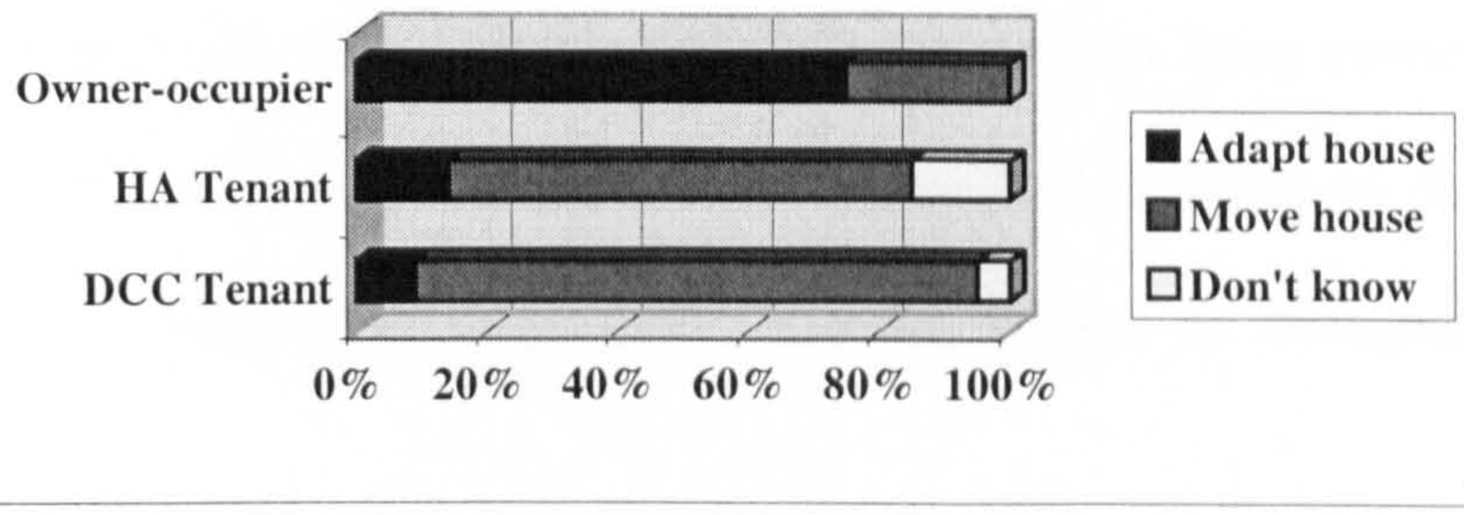
Social housing tenants appeared to experience the gravity of an inadequate supply of accessible and affordable housing more than owner occupiers through the frequent and often involuntary moves they had to make to acquire a suitable house. As Gillian testifies, after her third move, she has eventually found a house that meets her needs.

> *This house has made a big difference, all the moving you have to do isn't good. You wait so long for a ground floor, so I went from a first floor to third floor, to ground floor to here.*
>
> Gillian, interviewed 12/2/97

Yet paradoxically, despite the uncertainty and the upheaval associated with a move, the majority of council tenants (86%) said, given the choice, they would prefer to move house rather than adapt their present house (Figure 6.5). There are many explanations that could be put forward as to why so many council tenants expressed a desire to move house, one of which is that this finding is indicative of the overall bad state of repair of much local authority housing, the bulk of which is old and located within rundown, deprived neighbourhoods. However, I want to concentrate on an alternative explanation. The high number

of council tenants who were keen to move house suggests that they had little loyalty or sense of belonging to their neighbourhood. Furthermore, there is a certain symmetry in the desire of housing association tenants (70%) and council tenants (86%) to move house, despite the former living in houses that were well designed for wheelchair users. When these findings are considered alongside the low numbers of social housing tenants (43% LA tenants and only 29% of HA tenants) who said they felt like they lived in a supportive community, it would appear that social housing tenants as a generic group do not have strong links or roots tying them to their house or neighbourhood. In contrast, owner occupiers stated they were settled in their house and neighbourhood and would prefer to stay put and adapt their house (75%) rather than move house (Figure 6.5).

Figure 6.5 Interviewees preference to adapt or move house by tenancy



The desire of owner occupiers to stay put appears to stem from a stronger sense of attachment to their home. This perhaps occurs through the investment of time and money in a property (Saunders, 1990), and of a sense of belonging to a neighbourhood (67% of owner occupiers said they felt they lived in a supportive neighbourhood, where they knew their neighbours and could call on them for help if the need arose). This apparent attachment to a property, that owner occupiers appear to have and social housing tenants appear not to have, may also

be attributed to a sense of ownership and power to exercise choice and control over one's property. As illustrated above, social housing tenants felt disempowered and unable to influence their housing outcomes and this may have influenced how attached they felt to their house and neighbourhood.

The subjective feelings involved in developing a sense of belonging to a place are important criteria for judging an individual's social inclusion in a community. However, it should be noted that whilst owner occupiers were more likely to feel they could call on their neighbours for help and support than were social renters, very few interviewees, across all tenancies, were involved in community activities. There was little evidence of 'strong communities' the government believes to be essential to 'provide the bulwark against the development of social exclusion in individuals and families' (Scottish Office, 1999). Further research would be needed to determine whether social barriers (ie stigma) and/or physical barriers (ie steps) are preventing people with disabilities from participating in community activities and if so whether these barriers are likely to change over time, are place specific, or even class specific, ie tied to different types of tenancy.

A number of interviewees had strong feelings about where they did and did not want to live in the city. Living close to the centre of Dundee was a favoured location for some interviewees for it had the advantage of eliminating the need for transport into town and to shops. However, the experiences of interviewees living on or at the top of the short, but very steep slope from the city centre up to the Hilltown neighbourhood, reveals the reality of living close to the centre of

Dundee does not automatically eliminate physical barriers or the need for transport to get to shops. There were three interviewees living in the Hilltown neighbourhood, and no doubt Alex and Donald could relate to and corroborate Ben's experience.

> *It's like why did they build sheltered housing on a hill? This is where we're going to put our grandmothers who have trouble walking and people in wheelchairs, right where will we put them? There's a good site, on the Hilltown, we'll put them there at the top. Who's idea was that? Even if you could get down, how the hell are you going to get back up? 'Cab', 'Yeah where you going pal?' 'Top of the road'. Two hundred yards up the top of the road. I feel stupid getting a cab. I get a cab from here to the shop, 200 yards down the road, because if it wasn't on an incline I'd manage. So that was a mistake building sheltered housing at the top of the Hilltown.*
>
> Ben, interviewed 9/1/97

Every time Ben has to call a taxi to get home he is reminded of his physical impairment and how the topography of Dundee controls his geographies, but also of the insensitivity in the design and allocation of houses for people with disabilities; of housing decisions that have not incorporated the first hand knowledge of people with disabilities and consequently fail to recognise people's holistic housing needs and their need to be able to participate in wider society.

There was a further barrier identified by Alex that transformed the city centre from a highly attractive to a less attractive location for her, and that is the cobbles in the city centre. Alex's new purpose built flat is located at the end of a cobbled street, which is severely restricting her independence as she is unable to go out on her own because of the cobbles.

> *The cobbles are hellish. ... My social worker went, 'Have you been out in the town on your own?' I goes 'No.' There was once she (Alex's sister,*

Judy) came in and I says, coz she had blood on her leg, 'What happened to you?' She'd fallen on the cobbles, and she can walk. So I wouldn't even attempt it. I hate them cobbles, it's just as well I liked to ride on carnival rides when I was younger (laughing) bump, bump, bump, bump! Why have cobbles and why have tram lines, cobbles are for horses and tram lines are for trams, we don't have either and then why go and build houses for the disabled beside cobbles? What is the point? I mean you see even the cars have bother.

Alex, interviewed 11/4/97

With hindsight the interviewees who lived in and close by to the city centre were able to identify barriers and drawbacks to living where they were, yet the city centre remained a more attractive location than the council estates on Dundee's northern periphery. Dundee has a number of council estates that are presently being regenerated under the council's social inclusion policy. Prior to regeneration, the schemes are/were riddled with crime and drugs and stigmatised. These schemes are consequently avoided by much of Dundee's population, and none of the interviewees were willing to consider a move to any of these housing schemes. Penny and Ben predicted that moving to one of the schemes would exacerbate the social barriers they and their family encounter in their everyday geographies.

Like when I was speaking to the councillor, he says when they offered me a house, two weeks ago it was up in Ardler, at Rosemount Road, now my daughter stayed up there and it's absolutely hell. There's gangs all over the place, and I've got to watch like, because two of my sons have got special needs right, and like the bullying out in the streets like, you have to watch them a lot right, but to go up there, it would make their lives hell, I couldn't do that.

Penny, interviewed 5/2/97

I could think it would make people quite anxious, anybody in a wheelchair. 'Oh just listen we're going to take you out of a nice friendly warm environment by all your friends and where you know where everything is and shove you in the middle of a scheme where you know nobody, you've never been in this end of the town, you haven't got a clue

> *where you are, that's where we'll put you.' A normal person wouldn't like it, but never mind somebody who already has enough to cope with without having that kind of mental pressure as well.*
>
> Ben, interviewed 9/1/97

Although interviewees were quick to say they wouldn't want to live on one of Dundee's peripheral housing estates, many of the social housing tenants predicted that whilst housing for wheelchair users remains a finite resource they would have little choice or control over their housing, in relation to both house type and location.

Unlike social housing tenants, owner occupiers appeared to have significantly more power to influence housing outcomes, although the range of suitable houses available to them remains limited. Tom is an owner occupier who had moved from one of Dundee's peripheral housing estates to a middle class, principally owner occupied neighbourhood. He had choosen the house he moved into, based on its potential to be adapted to suit his needs and its location. Tom had felt socially excluded in his previous neighbourhood, yet moving house had been invigorating for him giving him a new lease of life, because physical and social disabling barriers have been eliminated from his local environment (Madanipour, 1998).

Susan: Was it accessible the house you were living in before?
Tom: Yes the house was accessible, but the actual vicinity it was in, wasn't very good, you know, I couldn't get out.
Susan: Why was that?
Tom: The ramps and everything, there were no ramps there was just steps, every place you went was just full of steps.
Susan: So you find this area is better?
Tom: Oh yes this is a hundred times better.
Susan: Are you feeling a lot more independent?
Tom: Yes, yes.

Susan: Would you say you've experienced any stigma yourself?
Tom: No, no. People in the Ferry are very, are very good with disabled people, I think.
Susan: Is that different to what it was like in Fintry?
Tom: Yes, yes.
Susan: Did you have problems there?
Tom: Not problems, but you always got the impression someone was going to be saying something.
Susan: You don't feel that here?
Tom: No, no.

Tom, interviewed 24/4/97

Tom raises two important points in the quotations above with regard to the potential of accessible housing, in isolation, to meet the housing needs of people with disabilities. First, he demonstrates that acquiring a fully accessible house will not unlock the door to an independent life, if the location of the house is physically and/or socially disabling. Secondly, Tom shows how moving house can have a dramatic impact on an individual's ability to get out and about in their neighbourhood. Tom's experience illustrates that space does matter, and therefore location matters (should matter) in housing allocations designed to facilitate the social inclusion of people with disabilities.

If location is so important it is understandable that when people are happy living where they do that they may resist pressure to move house. Morag faces the dilemma of many tenants in social housing of deciding whether to remain in unsuitable accommodation or to move to a new and unknown neighbourhood (Goldsmith and Kirby, 1977). She was one of only a few social housing tenants who wanted to stay put, and adapt her house. A house which she and her husband had invested time and money in, creating a place with fond memories in a supportive and familiar community. However, Dundee Council had told her that there are insufficient resources 'to go around adapting every house' and she

must move. Morag felt disempowered and silenced by a system that appeared to be unable to meet her housing needs.

> *I like my house, I like where we live, I dunna really want to move out. I mean every bush in that garden, we bought, we went to nurseries, there was nothing in that garden, not a thing, and it was up to the window with long grass, it was just a wilderness, and Jim done all that, cut out circles. Every bush and flower tells a story, that bush by the fence was got on one of our anniversaries.*
>
> Morag, interviewed 21/1/97

Under the Chronically Sick and Disabled Persons (Scotland) Act, 1972, home owners are eligible to apply to their local authority for a Home Improvement Grant to assist with the cost of adapting their property. Potential recipients of this grant are afforded the flexibility of staying put and adapting their house, if that is what they decide to do. Anna, for example, did not want to move house. Her family home, owned by her mother, was a base for social interaction, security, warmth and childhood memories. She successfully applied for a home improvement grant from Dundee Council to adapt the family home that has enabled her to remain at home with her mother, who is her full time carer.

> *As I say to the social worker, Anna's happy in this house, if she wants to go to a disabled house she can go. But she made it quite clear to me, that no way am I going out of here, unless it's really, really necessary, but if you can do things in this house for me, I want to stay. So when they decided that they could do it this way, she says well 'I'm quite happy'. So I said her happiness is important, if she's happy in this house, she might be put in a 'disabled house' with even more things in it, but what's the point if she's not happy? I says that's not any use, she's got everything around her, but she's not happy in it. I says that could tell on her health, she's happy here and she knows the people about here. That's the main thing.*
>
> Betty, Anna's mother, interview 31/1/97

Anna's mother highlights some of the real concerns expressed by interviewees with regard to moving house and moving to the unknown, fears that appear to be borne out by findings from this study and demonstrate two things. First, it takes time for people, and especially people whose bodies are outwith established cultural norms, to be accepted into a new community (see Chapter 5). Secondly, it appears that home owners are more likely to live in neighbourhoods that are supportive and friendly, than social housing tenants. This point is supported by the views expressed by renters and owner occupiers about their respective neighbourhoods, but the data available does not reveal conclusively whether middle class neighbourhoods are more accommodating of difference than neighbourhoods comprised of predominantly social housing.

It is evident from the debate so far that an accessible house is unquestionably a priority for wheelchair users, and housing providers in Dundee are working hard to provide a suitable house for as many of the city's wheelchair users as possible. However, there are other factors that need to be taken into consideration in the allocation process some of which are beginning to be recognised by housing practitioners (Scottish Homes, 1998; Homepoint, 2000). One of these factors is the importance of place in people's lives, and thus giving social housing tenants greater choice and control over where they want to live. In the earlier sections of this chapter on second hand knowledge and first hand knowledge it was noted that social housing tenants are more likely to encounter problems accessing relevant housing information and finding a forum to express their housing needs, wishes and wants. In relation to moving house, an inadequate, reciprocal exchange of information between service providers and service users appeared to

be contributing to an increased likelihood of social housing tenants receiving a less than optimum housing outcome.

The final section in this chapter retains the focus on the role of location in people's lives by exploring the importance to interviewees of having shops close by in an accessible environment. Having a local shop that is wheelchair accessible enables people to go out independently for short periods of time and is consequently a highly valued and sought after facility to be considered alongside a well-designed house. This appeared to be particularly significant for interviewees who lived alone and who didn't have a car.

Shopping and Car Ownership

> *Donald: Yeah I'd like some shops I could go to close by, so I could maybe nip round the shop or something. Coz I mean it is a wee thrill when you get to the supermarket, you know to go shopping, it's not what most men would say, but no I get a wee bit of a thrill.*
> *Susan: Are there any shops that you can get to around here in your wheelchair?*
> *Donald: Yeah there are plenty of shops I can go to if I get a hand. And see this hill here, very, very dodgy, who built houses for old people at the top of a hill?*
>
> Donald, interviewed 19/2/97

Donald is virtually trapped in his house, located as it is in the Hilltown neighbourhood, with no accessible amenities close by. His experience was not, however, unique amongst interviewees. As tales were recounted of having to wait at shop doors to be served, it became apparent that few interviewees had local shops that they could access independently in their wheelchair.

Like the chemist down there, I can't go into it, because all the counters are too close together, so the girls come to the door for me.

Helen, interviewed 6/2/97

Alex: Some shops are OK, but like the post office, there are steps up to it. Why haven't they got a ramp. Look if you're in a wheelchair, you're on Disability (Disability Living Allowance) therefore you have a book, therefore you have to cash it in the post office, so why can't you get in?
Judy: Otherwise you've got to rely on someone else to go and do it for you.

Alex, interviewed with her sister present, 11/4/97

Neighbourhoods were generally found to be inaccessible for people to negotiate in their wheelchair, and consequently very few interviewees spent time in their neighbourhood or using local shops, particularly if they had a car.

Susan: What's this area like generally for getting about in your wheelchair?
Philip: It's very bad.
Susan: Do you go out much around here in your wheelchair?
Gillian: Well I went along to the post office three years ago, in this chair, and it's got kerb climbers, so you've got to go straight on, and I toppled over, the kerb was too high, so I never went again. I'll go out with him, I trust him 100%.
Susan: But you wouldn't go out by yourself?
Gillian: I won't go out by myself.
Susan: Are there shops around here that you can get into?
Gillian: There's only one and Safeways, isn't there?
Philip: The pavements are all up and down.
Gillian: You know the trees the roots, it's all up and down. So I mean it's not accessible around here. So we go everywhere by car.

Gillian, interviewed with her husband Philip, 12/2/97

Susan: *Are you able to get around here much in your wheelchair?*
Morag: The kerbs are very high.
Ian: We don't go out, just as far as the car.
Susan: Is that because it's not easy to get around?
Morag: There's nothing really round here, there's none of the shops that I can I go in, there aren't any dropped kerbs.

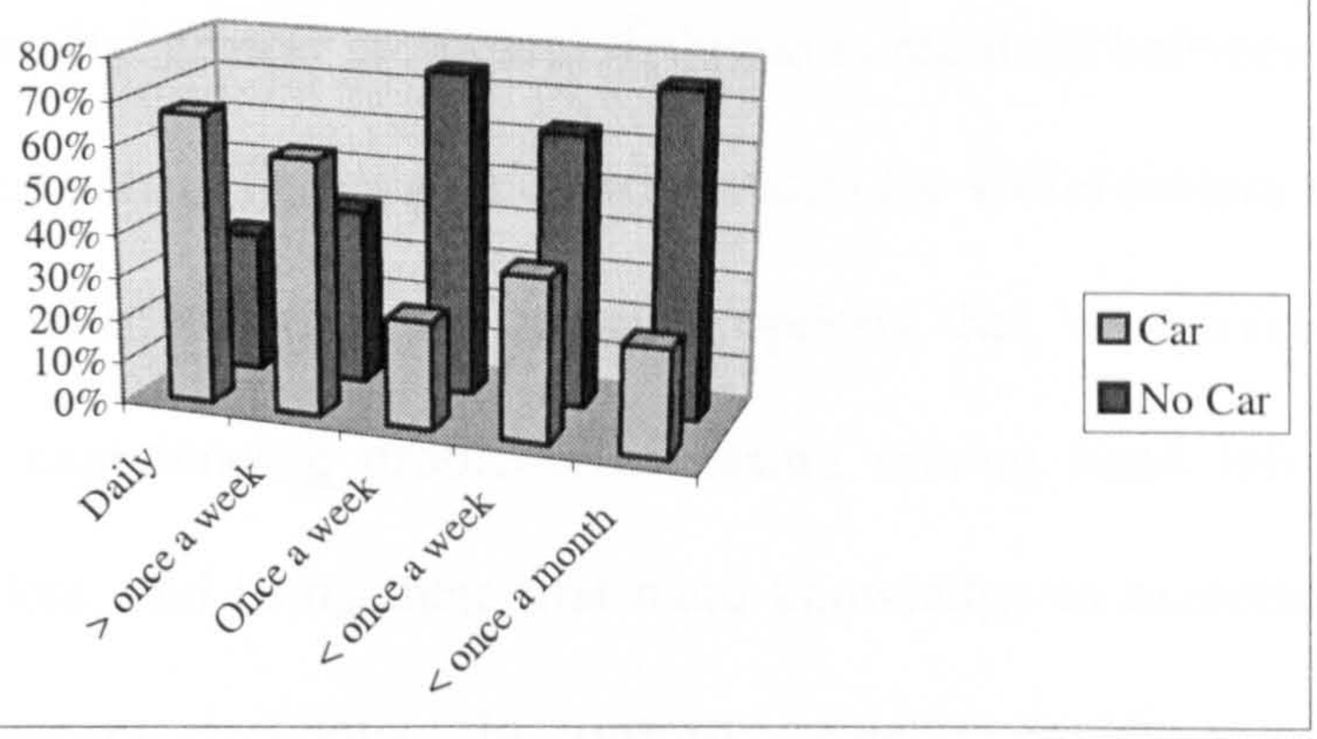
Morag, interviewed 21/1/97

Car owners were found to be venturing out into other parts of the city for socialising and shopping which gave them a greater sense of social inclusion and freedom. They had the advantage of being able to transcend their neighbourhood and broaden their geographies and places of shopping to include shops that were known to be accessible, in particular, as Zoe commented, supermarkets.

The nearest shops, are at least half a mile, in either direction, and that way is very uphill. No if you're going shopping now, you go to the supermarkets, because supermarkets are designed for trolleys, and therefore they're great for wheelchairs.

Zoe, interviewed 8/12/96

Figure 6.6 Car Ownership and Frequency of Going Out



Fifty two per cent of interviewees had a car and this appeared to be positively impacting on the frequency that they went out, especially on a daily basis (Figure 6.6). However, none of the interviewees who lived alone had their own car and this same group of interviewees were found to be going out less frequently than people living with a spouse/partner or with their family. In other words, people who were living on their own were more likely to be leading place based lives and be dependent on other people to take them out. Either way it appears that

place, and specifically the availability of accessible local amenities is particularly significant for this group of people.

CONCLUSION

The message conveyed by this chapter echoes calls made elsewhere to make people with disabilities more visible and vocal in society (Chouinard and Grant, 1995), to empower this section of the population as a means of addressing the social exclusion and marginalisation that appears as endemic in their housing experiences. In the realm of housing this requires a shift in the working practices of service providers and their interactions with their clients. The experiences of interviewees suggest that greater reciprocal dialogue is required between service providers and service users. This is particularly crucial for social renters who felt 'information poor' with regard to the housing options that were available to them. They were experiencing problems accessing second hand information from service providers, and using their first hand knowledge to exercise choice and control over housing decisions. In contrast, owner occupiers appeared to find it easier to access relevant housing information and were empowered through this knowledge base to exercise choice and control in the housing market, both with regard to the design of their house and its location. Owner occupiers thus appeared better able to diminish their experience of social exclusion and marginalisation within society through moving house or adapting their present house than were social housing tenants[5].

Mistakes are being made in the design (Chapter 4), location, and the allocation (Chapter 5) of disabled housing, some of which could be addressed if service

providers worked from a broader knowledge base. A base that included experiential data from people with disabilities, rather than one that is constructed and functions to meet the needs of the able-bodied. Enabling people with disabilities to have choice and control over their housing, whether they are owners or renters, could be an empowering experience that could have wide ranging implications. It could influence the ways people felt about and experienced their living spaces, it could establish a sense of ownership and belonging to a place, and it could impact on an individual's embodiment.

> 'The principle of empowerment further implies that the ability of individuals to exercise effective control over decisions which effect their daily lives is not an acquired 'once-for-all' characteristic, but an outcome of an ongoing process of reciprocity and negotiation between support and housing providers on the one hand, and clients on the other; it is as much about the process of provision as about the resources that are provided'
> (Edgar, et al., 2000:40).

Fundamentally, empowerment privileges 'the voice of the Other as a valid way of knowing' (Elliott, 1999:242).

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[1] Even with this information, social housing tenants may still feel under pressure to compromise and accept a property they are not entirely satisfied with as they are very conscious of having only three choices of houses before being relegated from the top of the waiting list.

[2] Homepoint's pioneering work, has created a framework of evaluation for the 800 agencies now giving housing related advice, to guarantee that the information given is consistent, accurate and of high quality (Homepoint, 2000).

[3] It was not within the scope of this study to look at informal carers but it should be noted that interviewees were keen for a family member to be at home to care for them, if at all possible, rather than have formal carers entering their home. Interviewees felt the relationship they had with their informal carer was one based on trust, love and respect and one which they had control over to influence outcomes. To accommodate the needs of disabled partners, children or parents, spouses, both male and female had given up full time jobs to become full time, unpaid carers.

[4] In Chapter 5 it was noted that 'insiders' in sheltered housing accepted the role of their warden in their lives, whereas 'outsiders' perceived the warden (and other formal carers) as an intrusion into their lives and as a form of surveillance.

[5] This finding should however be considered in relation to a study by Easterlow et al. (2000) that found owner occupiers with health problems have difficulties maintaining the upkeep of their home. Drawing on findings from a previous study (Smith et al., 1998) it is argued that renting in the public sector may produce healthier housing outcomes for people with disabilities.

7

DISABLED BODIES AND EMBODIED EXPERIENCES

INTRODUCTION

During the 1990s the body became a key concept in the social sciences as attention shifted away from the medicalisation to the socialisation of the body. The geographical imagination latched onto conceptualising the body as a social construct, recognising its relationship with social space (Gleeson, 1999). Lefebvre (1991:162) observes, 'it is by means of the body that space is perceived, lived and produced'. In geographical texts the body became a site of representation (Bell & Valentine, 1995; Pile & Thrift, 1995), a place 'that is spatially and socially positioned by cultural norms' (Dyck, 1995:308).

The juxtaposition of the social body alongside the medical body within the broader social sciences literature, mirrors theoretical developments within the field of disability studies, and specifically developments in the social model of disability. The previous three chapters have illustrated how, in relation to physical and social barriers associated with housing, an ableist discourse positions people with disabilities on the margins of Scottish society. The impaired body has been shown to be constituted by and through spaces and prevailing social discourses, and in a cyclical process, representations of the body were shown to be inscribed onto space. Sensitivity to the body has raised an awareness of 'whose bodies produce the city versus whose bodies inhabit it' (Harvey, 1996:278, cited in Gleeson, 1999:51).

The social model of disability serves to illustrate how the disabled body is socially constructed as representative of specific socio-spatial and temporal practices. Yet the social model has been criticised for homogenising the fluid, embodied experiences and multiple identities of people with disabilities and for failing to engage with their physical embodiment: their pain, fatigue and fear of dying (Crow, 1996; Morris, 1991). Disability theorists (Butler and Bowlby, 1997; Hall, 1999) have thus called for the physical body to be reintroduced into theoretical thinking, arguing that biology and society should be seen as reflexively linked: '[t]his would allow political space for the acknowledgement of differences of experience and interests amongst impaired and disabled people as well as maintaining an emphasis on the importance of 'society' – of power relations and of social discourses – in structuring differences' (Butler & Bowlby, 1997:418).

This chapter will elaborate on the debates on the body outlined above, to elucidate the lived, embodied experiences of wheelchair users living in a Scottish urban environment at the end of the twentieth century. The first section focuses on corporeality, the social body, and addresses the acceptance or non-acceptance of a disabled identity, and the mind/body dualism. The second half of the chapter turns to the question of physical impairment with a discussion on how people cope physically, socially and spatially with a body that is painful, tired, unpredictable and often out of control. The first section, entitled 'Social Embodiment' highlights the influence and impact of an *ableist discourse* on the body and identity formation, and the second section, entitled, 'Physical

Embodiment', highlights the influence and impact of *physical impairment* on the body and identity formation.

SOCIAL EMBODIMENT

In the social sciences cultural studies, feminism, postmodernism and poststructuralism have opened up a debate on difference, identity and the notion of the embodied self. Several different approaches have been used in theorising embodiment, ranging from essentialist understandings based on biological determinism through social constructivist accounts, to post-structuralists notions of the 'body as text' (Dyck, 1999). Geographers' interests lie in the linkages between the body and the negotiation of identity in place and space (Dyck, 1999). This has been achieved by health geographers problematising taken-for-granted assumptions about disability, illness and the body and demonstrating the social and political nature of health and disability. In so doing the hegemony of a biomedical discourse has been challenged (Dorn and Laws, 1994; Kearns, 1993). As Dyck (1999) argues, although bodies are marked through the language of biomedicine, they are reinterpreted in their living spaces and through social discourse. Feminists and other social scientists thus repudiate Freud's declaration that 'anatomy is destiny' (Gleeson, 1999:41), arguing instead that the body is a 'reflection of society' (Douglas, 1975), and that what matters is the body's representation, meaning and symbolism. These developments in the social theorising of the body have directly challenged causal connections between a person's biology and his/her social position (Hall, 1999). No longer can, for example, a woman's body, a black person's body or disabled person's

body be the grounds for a subordinated position in society. Kearns (1995) states that the fundamental nature of the changes presently occurring within medical geography are a shift from 'mapping disease to maps of meaning'. The cartographic metaphor is also adopted by Rose (1993) when she states, 'far from being natural, bodies are maps of the relation between power and identity' (Rose, 1993:32).

Gleeson (1999) adds a temporal dimension to theorising the construction of disability in different spaces and societies. From an historical materialist perspective he argues that 'human corporeality is a *historically and socially* specific phenomenon' (emphasis in original, Gleeson, 1999:43). Drawing on his own empirical work on disability in feudal and capitalist societies in England and Australia, respectively, Gleeson calls for research to avoid universalising the body across time and space and to understand how particular forms of embodiment are/were experienced in different times and places (Gleeson, 1999). Yet in arguing against universalising the body *across* time and space, Gleeson (1999) universalises the body with*in* particular times and spaces, leaving no scope for individual difference within broad temporal and spatial scales. In this chapter, I want to illustrate how the disabled body, far from creating a static, fixed identity, is fluid, multi-layered and constantly in transition, in Shilling's words it is always 'in the process of becoming' (Shilling, 1993:4). Following Dyck (1999: 121) '[t]he body as a static or essential 'object' is rejected, for it is understood as constantly in the making, embodying and contributing to social relations, and with its capacities constituted within cultural and historical specific moments'.

Previous chapters have suggested that the strategies adopted by interviewees to negotiate disabling barriers are intricately linked to how they experience embodiment (Moss & Dyck, 1996). This chapter moves away from concentrating on physical and social disabling barriers, to focus specifically on the impact of social and physical barriers on disabled bodies: bodies that were overlooked and excluded in the design and creation of inaccessible environments. It addresses how people with disabilities negotiate their identity within a physically impaired body, an identity, which for wheelchair users, is dependent upon and includes their wheelchair as an extension of their biological body.

Negotiating a Disabled Identity

In a 1998 paper Dorn draws on the testament of one female wheelchair user, Patty Hayes, to discuss her transition from denial to acceptance of her wheelchair. Until Patty had overcome her fear of her disability and her wheelchair, she was 'incapable of learning ways of navigating through her environment' (Dorn, 1998:192). Patty Hayes describes the process she experienced in learning to interact with her wheelchair and her environment in four-stages (Table 7.1).

Patty's initial rejection of her wheelchair as limiting, restrictive and unwieldy, was replaced by her seeking to understand her new identity through the advice of 'experts'. As Patty's confidence in herself grew alongside her maturing disabled identity she relied less on the advice of experts and started to listen to her own

body knowledge and intuitions. As Dorn (1998) notes, she began to work with the chair rather than against it. 'This allowed her to resynchronise the three terms: body, mind and chair' (Dorn, 1998:193). During stage three Patty coined the term 'bodychair', to encapsulate her new identity that had assimilated the use of her wheelchair as an extension of her body. 'The wheelchair, if you will, has become my external skeleton, and I do rely on it. ... I realise, in other words, that I have to function *while in the chair*' (emphasis in original, Hayes, 1995, cited in Dorn, 1998:193). By stage four Patty had become a disability activist fighting for disability rights, confident in her role as a disabled woman. The use of Patty's home space and wider urban space were dramatically transformed once she had come to terms with her declining health and negotiated an identity that enabled her to live with and through her wheelchair.

Table 7.1 Patty Hayes' Four Stage Development of a Disabled Identity

Stage 1	Disableism and denial: attempting to ignore the chair
Stage 2	Rehabilitationism: looking to experts for advice on how to make accommodations for the chair
Stage 3	Independent functioning: designing for the *bodychair* in use
Stage 4	Disability rights: taking her wheelchair out of the house and into the streets as a disability activist

(Dorn, 1998).

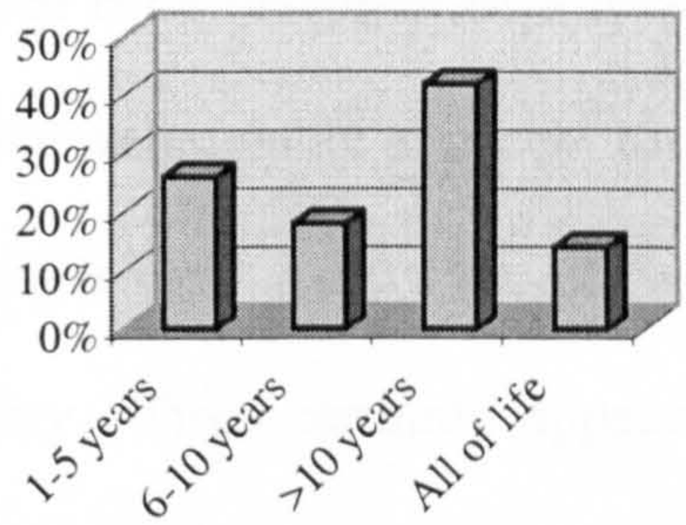
The four stages identified by Patty provide a framework from which to consider the experiences of other wheelchair users. But that is not to overlook the fact that the framework reflects the process Patty went through in accepting her disability, and it does not mean that other people will naturally move through all the stages or move chronologically through the stages. However, I found a

number of interviewees who appeared to be moving through similar stages to Patty in their maturing acceptance of both their physical impairment and their wheelchair. The following two sections first, trace interviewees growing understanding of what it means to be disabled in a society that provides little guidance on how to be disabled. The section addresses the process interviewees went through to accept their wheelchair, to learn to manoeuvre in their wheelchair and a combination of the two as the wheelchair was transformed into a 'bodychair'. The second section looks at the strategies adopted by interviewees attempting to resist a disabled identity and being labelled as disabled.

Accepting a Disabled Body

> *Accept me for who I am, I'm a person with wheels, not wheels and a person.*
> Zoe, interviewed 8/12/96

Figure 7.1 Length of Time Interviewees had used a Wheelchair



Only 7 out of the 50 interviewees had congenital impairments, the rest had lived a large part of their lives as able-bodied (Figure 7.1) and were 'in the process of becoming' (Shilling, 1993:4), of renegotiating their identities based on their constantly changing physical ability. They were making the transition from an

able-body that was perceived to conform with axiomatic standards of normality, to a disabled body, perceived to be abject and non-conformist.

Previous chapters have illustrated how certain spaces and places are visibly inaccessible for wheelchair users, and represent the power of space to delineate and curtail the spatial activities of people with disabilities. Other spaces are, however, constructed as inaccessible by wheelchair users themselves. Barriers are created through people feeling out of place and excluded in public spaces or lacking the confidence to go outside of their home in their wheelchair.

> *I wouldn't go out in my chair, it's just me, it is definitely me.*
> Beverley, interviewed 18/2/97

> *I'm always in, see I'm in a wheelchair, I don't like going out now.*
> Donald, interviewed 19/2/97

Donald and Beverley are both at the stage of denial, according to Patty Hayes four stage transition towards acceptance of a wheelchair. It was not uncommon for interviewees who had been disabled for a relatively short period of time to admit like Amy that, they were unable to accept the reality of their changed body status, 'I'm not accepting it yet'. Amy's use of 'yet' suggests that over time she may accept her disability. Time certainly appeared to be a significant factor, influencing how far interviewees had moved along a continuum of acceptance (from non-acceptance to acceptance) of their impairment and disability. Many interviewees talked of needing time, or having needed time, to come to terms with their physical impairment and accepting their wheelchair as a part of them, as an extension of their body. In the following quotations, Gillian and Sara

recount the time that elapsed from them acquiring a wheelchair and them actually using it to venture outwith the boundaries of their home. They emphasise that until they had come to terms with their disability, the boundaries of their home became self-imposed barriers to the outside world, preventing them from going outside for months or even years.

Gillian: Well I think I go out more in this house because I've got used to being in a wheelchair. Whereas before I just didn't like, just the thought of being in a wheelchair, people looking at me, some people did they went 'Ahh, what a shame'. They didn't understand that I could be just like anybody else and just like them. ... They gave me a wheelchair, and I got very agoraphobic, because people were looking at me, well I thought they were looking at me in the chair, so I was in my bedroom for two years, never been out of my bedroom for two years.
Susan: How do you feel now about going outside?
Gillian: I go out every day coz now I know, you know people just look at the chair first you know, and you've just got to tell them.

Gillian, interviewed 12/2/97

I've got over the initial shock, it sounds awful I know, but I had not been going out simply because at first I was in a wheelchair. I decided the only way I'm going to get accepted, is to go out in the wheelchair, and 'eh face everybody. I thought right get in your wheelchair, go in it and let everybody see the way you are now, so they will accept it quicker. Now I can speak to people and people don't bother that I'm in the wheelchair. I'm still Sara, you know even though I've got the wheelchair. And people look past that now, they look at me, they don't see the wheelchair, you know, so that's a good a thing.

Sara, interviewed 25/3/97

Liz illustrates how she transcended an initial reluctance to assimilate any aspect of disability into her life, either through her subjective embodiment or symbolically through the physical design and layout of her home.

I don't have any regrets about taking them (grab rails) out. I probably wouldn't do it now if I was moving into a new disabled house, because I'm so many years into my illness now and I'm coping better now. When

I first moved in I hated anything that made me look disabled. You know, so everything got thrown out. But no I wouldn't do that now. I'm not quite as bad as that (laughing).

In the beginning I felt like I was like an alien, that had just landed here, you know. Not so much now though, no. There are lots of things that I can't do. There are lots of things that a lot of people can't do, short sighted or long sighted, so they can't do what perhaps I can do. So I think most people are unfortunate in one way or another, I think if people thought like that then things would be different, you know instead of just what they can see. A lot of them think because you're in a wheelchair or are on sticks, you don't have a brain. You know they don't see beyond the actual aids that you use.

Liz, interviewed 13/3/97

Liz raises many pertinent issues in the second quotation above with regard to tolerance and valuing difference, without being judgmental. She suggests that these attributes only really became a part of her once she had accepted her own disability. It was only then that she could see how pliable the concept of disability was and how it could be applied to everyone in some aspect of their life, without prejudice or discrimination. Drawing on the experiences of Liz, and others, it is apparent that the process of moving along the continuum towards accepting her disability involves a steep learning curve: learning how to be disabled.

Chapter 6 addressed the problems interviewees experienced in accessing information about housing issues. Similar problems were evident amongst interviewees seeking to 'learn' how to live within a disabled body. With the prevalence of an ableist discourse that divulges little about living with a disability, interviewees were finding it hard to make the transition from able-bodied to disabled status, for the simple reason, as Alex clearly articulates, they didn't know how to be disabled.

> *I know I'm really bad at being disabled, but I want to write a book about being in a wheelchair, because I was looking for some books, I didn't know anything about it.*
>
> Alex, interviewed 11/4/97

Alex acknowledges that before she became disabled, when she identified as and lived through an able-body, she never encountered disability, she never thought about it, because it never entered the world that she lived in. Furthermore, when Alex tried to find some literature to guide her understanding of what she was going through, she was faced with an array of books that medicalised her body, and made her believe that it was her physical body that had repositioned her from the centre to the margins of society. She encountered a lack of information and resources to draw on to help redefine and negotiate her new identity. Dyck (1995:308) talks of women with disabilities living in 'spaces of silence' for the women in her study had comparable difficulties 'gaining access to stocks of practical knowledge of managing chronic illness that exist outside the biomedical domain' (Dyck, 1995:308). Embodied knowledges arise through 'interactions with the environment – and ... do so in distinctive ways if our bodies are differently 'sexed' or if they are physically or mentally 'sick' or 'disabled' – to shape our sense of ourselves in time, space, period and place' (Philo, 1996:38, quoted in Dyck, 1999:121). When the spaces that people interact with silence and exclude their bodies, defining an identity becomes problematic.

> '... as lived bodies we are not open and unambiguous transcendences which move out to master a world that belongs to us, a world constituted by our own intentions and projections' (Young, 1990b:65).

In the above quotation, Young (1990b) was writing specifically about women, but her argument could equally apply to people with disabilities and the difficulties they encounter defining their identity in a society that is constructed and functions to meet the needs of the able-body.

Rather than seeking embodied knowledge through written texts, Liz and Penny sought a better understanding of their disability by attending arthritis group meetings. The opportunity to share experiences, either through informal socialising or formal support groups can, as Wilton (1998) suggests, provide vital resources for many people and can be instrumental in helping to establish a feeling of control over an individual's health. However, both Liz and Penny, to their dismay, found their respective meetings were dominated by older people who questioned the legitimacy of their presence at the meeting through disputing whether their perceived healthy bodies were arthritic (see Chapter 5). In their meetings Liz and Penny felt unwelcome and excluded from gaining a deeper understanding of their physical and social embodiment, because the gatekeepers to their meetings found it difficult to conceive of young, seemingly healthy looking women having what is perceived to be an older person's disease. Chouinard (1997) writes of her own experience of being misperceived as disabled to illustrate the ways that ageism and ableism combine 'in restrictive assumptions about what disabled bodies [sh]ould be like' (p.381).

Fortunately Liz found another source of support and knowledge and gained tremendous strength and understanding through sharing disabled experiences with young people with arthritis.

I used to feel like I was the only one, I didn't know anyone else locally with arthritis when I was first diagnosed, I was only 22 when I was diagnosed, and I felt very, very isolated. Then I met another young girl one time I was in the ward and she was the only other person I knew with it and it was her that got me involved in young arthritis care. They were running a course, a week of seminars, ... and it was just great because you went there and everyone was saying things, gosh that's exactly how I feel, what, this is amazing. Your words were coming out of everyone's mouth, everybody was in the same boat, which was really good.

Liz, interviewed 13/3/97

In talking to Liz it would appear that she has had time to adapt and develop an identity that embodies her changing health status. But this process of acceptance takes place in disabling spaces that act as constant reminders that wheelchair users are excluded and marginalised from participating fully in society. The significance of this fact cannot be underestimated in considerations of the negotiation of an individual's social embodiment.

Well I work with the British Polio Fellowship nationwide with their headquarters. Because there are so few people surviving now who have polio I do feel very isolated. But once you're in a wheelchair, one disability, it doesn't matter what the name of the disability is, it's the wheelchair that's the problem.

Iris, interviewed 28/1/97

See I struggled for so many years, trying to walk see, trying really hard, I was in so much pain I was just disgusted with the whole situation. For a long time I felt God, I wanted to die, that's how bad I felt. But I feel like when I got the wheelchair I felt brilliant coz I could get out. I can go and do my own shopping, I no have to ask the kids or my old man to go and get the shopping, which was great. In fact sometimes I feel bad about it now, coz if I go into a shop and like my husband tallies on behind us, 'What do you want?' ken coz I can do this. ... Like as I say with the wheelchair I can get out and about, but I still feel, I'm not really angry that I've got the wheelchair, but I'm angry that I still canna do the things I canna do and go the places I wanna go, you ken.

Penny, interviewed 5/2/97

Significantly Penny did not appear to go through a process of adjustment or resistance to using her wheelchair once she had received one. However, the design of her house and urban space prevent her from maximising the use of her new 'bodychair'. Thus whilst Penny's wheelchair has given her a new lease of life and independence, the built environment is a constant reminder of her positionality, that prohibits her, and other wheelchair users, from moving in frictionless space. A further constraint that influences how people perceive their disability and the process of accepting a disabled body is the perception of family and friends towards their changing physical status.

Family and Social Network Responses to Disability

As humans we are innately social beings, we live in social units and draw heavily on other people to help define the boundaries of our identities and ourselves (Sibley, 1995). As Sara explains, the process of negotiating her disabled identity has been contingent not only on her ability to accept and negotiate her declining health but also Dave, her husband's view of her disability. Dave has been unable to accept that his wife must use a wheelchair, and has subsequently severely curtailed her use of her wheelchair (to the extent of removing the battery from her powered wheelchair).

> *It's been hard to bear, and I think simply because, not just that I've had to come to terms and had to work through my pain myself, but Dave's non-acceptance has been even harder you know for me to get through as well. OK he'll bring me a cup of tea up in the morning, and this morning he cleaned and tidied up for you coming, but that's not usual.*
>
> Sara, interviewed 25/3/97

In contrast to Sara, Gail's husband, Bruce, has supported her through her changing health status, and in the reciprocal relationship that is their marriage, Gail has supported him by being strong and preventing her physical impairment from impacting on their relationship.

> *Bruce was a typical male, from the forties, you know, where mother and wife did everything, the only thing I can say is that now that Bruce has got more to do, he copes rather well, because I'm there to tell him what to do, how to do it. And as far as the disability goes, and I've said this before, and Bruce would agree as well, he copes quite well most of the time, simply because I cope. I mean if I was the type that just said 'Oh I can't do it', 'Oh leave me alone I can't do it', he'd be away. That's another thing he does not give me any pity and sympathy and all the rest of it. Coz I have been diagnosed MS for twenty-five years, he's had a long time, like me, he's had that time to adjust. But because I'm such a stubborn, independent person, I mean, some people in that position, they just wouldn't have a row, that's not true for me. I mean if I have an opinion, I'll make sure Bruce knows if he thinks I'm wrong, and he'll not be long in telling me if he thinks I'm wrong.*
>
> Gail, interviewed 6/2/97

In the following quotation, Judy, Alex's sister illustrates how her perception of people with disabilities and the accessibility of spaces has changed through living with her sister as her health has deteriorated.

> *Since she's been in a wheelchair I've really begun to think about things for disabled people. I tend to look at places differently now, how to get in by a wheelchair and all that, whereas before you'd just walk past and not think about it. We were both really bad, and look at people and say why are you walking like that.*
>
> Alex's sister, Judy, interview 11/4/97

The three quotations above suggest that prior to family members becoming disabled they viewed the world through the lens of ableism for disability wasn't a part of their lives, and consequently they never thought of how society and social space discriminated against and excluded people with disabilities. The accounts

by Sara, Gail and Alex's sister, Judy, are illustrative of the different stages family members appear to pass through, or adopt, in relation to accepting disability within their family. Sara's husband is still in the stage of denial, Gail's husband has accepted her disability, but according to Gail, still doesn't think and see with disabled eyes, whereas Alex's sister, Judy, challenges ableist practices and attitudes in the way she now reads the landscapes she encounters. Judy is consciously viewing landscapes anew, seeing access or barriers wherever she is, irrespective of whether she is with her sister. Such thinking has been internalised by Judy, it has become a part of her everyday perception of the world.

When the examples cited above are considered in relation to the four stages that Patty Hayes experienced in accepting her disability, it appears that learning to acknowledge and understand one's disability takes time and is related to living with disability or in close proximity to someone who is disabled (see Chapter 5). Certainly interviewees with young children were particularly sensitive to the benefits their children acquired by growing up in a house with a disabled mother or father. They felt their children were learning to demystify disability by understanding what it meant to live in and through a disabled body. By providing their children with a positive role model, their children were gaining a perspective on the world that could resist established norms and recognise bodily differences without prejudice.

> *You've got to change your whole attitude, the way you feel, the way you think. For the better in one way, you know I think for the kids. Nicholas's friends for example they come in and see me running about in this and they'll start asking questions. 'Oh how does that work?' and 'What's that for?' They just begin to think that it's normal.*
>
> Amy, interviewed 12/2/97

Thus the constituent parts of an individual's home (both the people and the building itself) appeared to influence interviewees' subjective embodiment. Friends also impacted on this process. Interviewees' transitions into a disabled body appeared to trigger a variety of responses from their friends, which ultimately led to a filtering process, whereby judgmental and intolerant 'friends' were sifted out from their social networks.

Susan: What about friends, do you find people treat you differently now you're in a wheelchair?
Jim: I get that feeling. I used to ask people, 'Am I from another planet?' Ken nobody's speaking to you and that. 'Am I green?'
Jim, interviewed 27/2/97

The way people treated us, you need to know you can trust friends to go out with, who aren't going to look at you or feel embarrassed, I mean, none of my friends feel embarrassed. Well I lost a lot of friends, well I lost a lot of people who I thought were my friends, and I've been left with three or four friends but they are genuine friends, and when I go out they are not embarrassed in the slightest, they've got so used to it that they don't even notice it anymore. ... But that offended me when people decided oh you're disabled now, a lot of people just left and I thought yeah you're the only one's who see me as different me, the other friends don't see it like that, to them I'm just Ben, that's all I am to them I'm Ben.
Ben, interviewed 9/1/97

Liz has also found that her social life has been curtailed, not only because of her physical impairment, but by her friends inability to understand her impairment and the need to be patient and flexible to involve her in their social arrangements.

Susan: Do you feel that you are restricted now as to where you can go and how you can socialise?
Liz: Yes, it breaks friendships. Coz when I was first diagnosed people used to phone up, to my mum's, that was where I was before I got married, to say, 'Do you want to go out on Friday?' 'Oh yeah that'd be great'. Friday and Saturday I'd be absolutely gobbed

and I couldn't do anything, and they kept phoning for a while, then it just sort of dwindled off. It was like she's not making an effort, so why, it was like they couldn't grasp, that you could maybe feel OK in the morning, but be very, very sore by night. They couldn't grasp this, they're all able-bodied, so why should they have to, you know. I was probably exactly the same when I was like them, so yes those friendships sort of dwindled, we see each other occasionally, but the friendship, the bond isn't there.

Liz, interviewed 13/3/97

The interplay between an individual's social world and their social embodiment has been well documented by Dyck (1995, 1996) in her studies of the complex interweaving of space, physical impairment and gender in the everyday lives of women with disabilities. Dyck has focused on the contested body and lifeworlds (1995), home space (1996) and work spaces (Moss and Dyck, 1996). The latter paper addresses how material and discursive bodies combine to create identities for women with disabilities in their working environments. Dyck's 1995 paper concentrates on how women's use of their home and neighbourhood changes after leaving paid employment. Employment was not a topic that this study set out to cover, yet interviewees broached the subject independently and on most occasions when this happened it was to discuss their dismissal from paid employment. Interviewees' physical impairment had encroached into their working spaces in a variety of ways. Some interviewees were unable to continue in their job as their working environment became inaccessible with their changing health status. Others felt that they had been unfairly dismissed as a consequence of their deteriorating health, and their employers' perceptions of their ability/inability to perform as expected in a 'normal' 9 to 5 job. Although with hindsight many interviewees admitted that they were probably unable to continue working in full time employment. Iris, however, knew she was capable of continuing in her job, but she felt that her colleagues were prejudiced and

discriminated against her for precisely that reason. Her colleagues couldn't accept that a body that they perceived to be abnormal could perform effectively in a normal work environment.

> *It still embarrasses people, there are still so many people who still think people in a wheelchair don't have a brain, and once you've knocked that barrier on the head you can go ahead. It's the same with professionals, doctors, teachers, they see someone in a wheelchair and they go, 'Ahhh', you know. I've been through a break down because of it at my work, and it took me 7 years of climbing out of the pit as a result of the loss of self esteem that put me into it. No matter how much I struggle there's no way I'm going back there [into paid employment]. Once I'd lost my parents I really struggled to find similar support, I certainly didn't get it at work, I've had it in education departments, I've had it at the College of Commerce, but there's a need for it both by teachers and by people at work. When you're doing what is the same sort of level of a job, in a place like Tayside House, as it was, in the region, then people do not like you being able to do your job as well or better than them when there is nothing physically wrong. People would still like to treat you as a second class citizen, if they can get away with it, but you hopefully will prevent that.*
>
> Iris, interviewed 28/1/97

Iris highlights the prejudice that people with disabilities are exposed to in their everyday lives, and the problems that this social group of people face in negotiating a disabled identity when society prejudges them. This point is reiterated by Helen who appears to position herself on the boundary between acceptance and non-acceptance of her disability. She prefers not to dwell on the reality of how the society which she lives in uses her body to position her, de facto, both socially and spatially on the margins.

> *I feel sometimes I don't like to dwell on the fact, I'd rather just keep that out of the way. When I was at college, because I was doing a computing course I was equal with everyone, we all had to use the keyboard, and I forgot maybe that I was in a wheelchair and it only came back to me when you go to the loo or something.*
>
> Helen, interviewed 6/2/97

Helen illustrates that negotiating her body in disabling spaces is a constant reminder that she, as a wheelchair user, is excluded and marginalised from participating fully in society, as such she doesn't appear to fall within any of the four stages experienced by Patty Hayes. She is neither in the stage of denial (stage 1) nor is she living through a 'bodychair' (stage 3). Rather she is resisting being labelled as disabled and being forced to live a disabled life: a life which has been structured by prevailing socio-spatial practices and expectations of what a disabled body can and should do.

Resisting a Disabled Identity

> *I'm part of that group, but not through choice. I was born like this, I've got to make the best of it.*
>
> Kevin, interviewed 2/4/97

Kevin, like Helen, appears to be resisting a disabled identity. He has integrated himself spatially into mainstream society, through exercising choice and control over the design and location of his house. In stark contrast, he has limited choice and control over the process of society labelling him as different, as disabled, as embodying an abject body. Kevin is aware of the power of the labelling process and thus resists having an identity imposed on him and being classified as 'disabled'. He calls for people to be treated as 'individuals' so that he and other people with disabilities can choose how they define themselves, rather than being forced by society to be part of a group one doesn't necessarily choose to identify with.

Through resisting a disabled identity, Helen and Kevin do not seek to celebrate their difference, rather they seek to hide their difference, to camouflage it within mainstream society. This point can be clarified by distinguishing between resisting the body as site of oppression, with the body as a site of resistance (hooks, 1990; Butler & Bowlby, 1997). Where the latter refers to remaining on the margins (hooks, 1990), to celebrate and take 'pride in our abnormality, our difference' (Morris, 1991:17) to challenge hegemonic definitions of the deviant body. Dyck (1996) found that not all people with disabilities are willing to give up the non-disabled strands of their identity without a struggle, as a female interviewee in one of her studies comments.

> 'I think it's my able body, my attachment to being strong, tough. I mean most of my life I was the one who had a lot of energy. ... I just don't want to identify with the disabled'.
> (Dyck, 1996:18).

The notion that bodies are sites of representation, mirroring prevailing hegemonic discourses, appears to lead individuals to interpret or resist their body image in relation to societies established norms. A common reaction to people with disabilities is grounded in the belief that those with impaired bodies must also have impaired minds (Butler & Bowlby, 1997). The essence of this misperception is captured in Helen's reference to the now discontinued Radio 4 programme, run by people with disabilities, entitled 'Does He Take Sugar?', which is illustrative of the mind/body dualism. This constructed dualism posits a weak body as being synonymous with a weak mind, an abnormal body with an abnormal mind. This binary thinking may help to explain why people resist identifying with the disabled.

Helen: At the beginning when I started, it was like 'Does she take sugar?', and things like that. Mum's the sort of person that'd say, 'Well I think you should ask Helen' and now if they said something over my head I'll sort of say 'Yes, she does'. Now I'm learning, at first I think I was a wee bit frightened at first to say something, now I think I've learnt that if you don't say something people will think, they have a habit of thinking that physically handicapped, must be mentally handicapped.

Susan: How does that make you feel?

Helen: It makes me feel annoyed, but that's society, unless they're educated and unless they've got experience, most folks shy away and once they hear that I've got a speech problem it might, they immediately shut down and they don't listen.

Helen, interviewed 6/2/97

Mind/Body Dualism

Mind/body characteristics have been artificially separated in the past by fixed understandings of what constitutes illness, physical impairment and mental healthiness (Butler and Parr, 1999). These fixed understandings of the mind/body dualism have their roots in fifteenth and sixteenth century understandings of illness and the body (Hall, 1999). Hall (1999) argues that at this time the body became the realm of doctors and biologists and the mind the concern of the church and philosophy. The body was increasingly understood as a machine made up of many parts, but emotions, fears, and pain were not among the concerns of medicine. This understanding laid the foundations for the development of modern medicine in the nineteenth century, the rise of medical science, surgery and drug treatments and the focus on disease and the curing of the ill body (Hall, 1999).

Feminists argue that in patriarchal society the mind/body dualism became naturalised in the male/female binary relationship, where the body emerged as the 'Other', the weak and dominated partner of the mind (Longhurst, 1995).

> ' ... an essential part of being a woman is that of living the ever present possibility that one will be gazed upon as a mere body, as shape and flesh that presents itself as the potential object of another subject's intentions and manipulations, rather than as a living manifestation of actions and intention. The source of this objectified bodily existence is the attitude of others regarding her'.
>
> (Young, 1990b:66).

Shakespeare (1994) states that this process of objectification, through the gaze of the powerful, is also experienced by people with disabilities. They and their bodily impairments are often looked at as objects of sympathy or social or medical curiosity. Drawing on the work of Gardiner (1995), Chouinard (1997) argues that these sorts of reactions to people with disabilities are common because, 'like children, an individual marked by a disabling difference is regarded as an 'open' person who can be approached with less reserve and respect than the 'average' adult' (p.381). Carol illustrates this point in the quotation below, during the interview with her mother.

> *Megan: We do a lot of travelling for the [Disability] Society, right so, it's me that carries the card, coz its me that has the position. But they still, and this is where the arrogance comes in, they still always address the man, or whoever is standing on their feet, they would never think that you had enough brain power sitting in a wheelchair and sometimes like the aggression sort of comes out if you know what I mean.*
>
> *Jimmy: I usually say I'm nothing to do with that, it's her name that's on the card it's nothing to do with me, 'Ah but you can sign it coz we canna get the book down there', 'No I canna'.*
>
> *Carol: Yeah and I hate people coming up to you and thinking they can pat you on the head, coz that is really, coz like they won't tap you on the head would they?*

Megan, interviewed with her husband, Jimmy and her daughter Carol, who is also a wheelchair user, 28/1/97

The process of objectifiation, Butler and Bowlby (1997) argue, impinges on the experiences of embodiment of people with disabilities, where their difference makes 'normal' people feel uncomfortable. Central to constructions of normality is the process of Othering and the separating out of body and mind differences (Butler and Parr, 1999). This 'separating out' of body and mind is seen by feminists as the outworking of dualistic understandings of the self and the Other, the 'normal' and the 'abnormal', the productive and unproductive, the 'sane' and the 'insane', the attractive and the disfigured. In recounting their experiences of being 'treated like an idiot when you're disabled' (Alex), interviewees suggested that in public spaces they are exposed to this process of Othering and the assumption that a weak body is synonymous with a weak mind.

And I also feel like, see like you're asking for a quarter of cold meat or something at a counter, and your husband's there or someone's with you they don't look at you, they dunna want to ken you, they'll look at the other person, "What else do you want?" But my husband, like yesterday we were at the council, he says he pointed to me, I didn't notice this at first, but he pointed to me, he says, 'This is who you're dealing with, ken, it's not me'. Ken so I felt a wee bit better coz he said that. The woman didn't want to ken me coz I was in a wheelchair. Some people look at you as if, not coz you're disabled, but that you're stupid that you're in a wheelchair, right I've found that out loads of times, you're labelled.

Penny, interviewed 5/2/97

You know at first it was like if I asked for something in the shop like a pound of sausages, they would say to him (Philip, her husband), 'A pound of sausages?', and they'd look at me as if to say, did I get it right. Now I give the money and if they give him the change, he gives it them back for them to give it to me.

Gillian, interviewed 12/2/97

The creation of dualisms is the end result of the innate process of defining oneself in relation to Others, that inevitably leads to hierarchies of Othering (Sibley, 1995; Wilton, 1999). In relation to the mind/body dualism mental differences are somehow rendered as less desirable and acceptable than physical impairment (Butler and Parr, 1999, see Dear et al., 1997). It is apparent from the examples cited above that interviewees resisted being associated with mental impairment, they sought to dissolve the mind/body dualism by stressing a weak body was not synonymous with a weak mind, in doing so they sought to emphasise their closeness to an able-body. In so doing, rather than highlighting the normality of a disabled body and celebrating their difference, some interviewees distanced themselves from people who were perceived to be 'more disabled' than they were themselves. They imposed a hierarchy of Othering on other people with disabilities based on an individual's visible impairment. Dear et al. (1997) drew attention to this hierarchical ranking of least to most preferred types of disability amongst able-bodied people. What this study reveals is that the same process appears to be operating amongst people with disabilities as they reproduce ableist imagery and thus the characteristics of 'internalised ableism' (Kichin, 2000:215).

> *I'm all for living with normal people, coz see the strange thing is see when you're alright bar your legs other disabled people can snub you. ... Ryan, like has a really bad attitude, you can tell he's thinking, 'Why are you pushing yourself and I'm not'. Well last time I was sitting in that chair, and he goes, 'It's alright for you'. But I goes, 'I can't go out without her, I'd like to, but I can't'. ... And remember that time we were up at Rockwell and I was talking to that woman and I said it's just my legs, that one plays up most, and she said, 'Well you must feel like a fake!' You know what I mean, other disabled people can snub you because you aren't as bad as they are. ... So if I was in a block with other disabled people they would snub me, because I am not as disabled as them. So when it's just your legs you're more accepted by normal people*

> *than you are by more disabled people, that's how I see it, you wouldn't think so, but you are.*
>
> Alex, interviewed 11/4/97

These findings illustrate the heterogeneity of people with disabilities and suggest that, as a social group, they are mirroring, on a micro-scale, the internal hierarchies and processes of Othering and normalisation that operate on a macro-scale within society. The findings also expose the power of prevailing social discourses to influence how people interpret their embodied experience of health, disability and illness (Wilton, 1999).

There is a salient message that appears to be reiterated time and again by interviewees and that is, that societies attitudes towards people with disabilities need to be fundamentally changed. Disability activists are attempting to address this problem and contest privileged knowledges of disabling differences by guiding able-bodied people to overcome their inhibitions about disability. This is being done by portraying positive images of people with disabilities that can challenge the mind/body dualism and extend the boundaries of socially accepted norms. Various artists have accepted this challenge, in photography (Hevey, 1992, McGill, 1999) and dance[1] (Stanford, 1999). Photographers like Alexa Wright seek to challenge the boundaries of disability and normality through their work. 'All of people's differences become normalised as you get to know them; I want the images to continue the process of normalisation for people' (Wright, quoted by McGill, 1999:16). The success of the 2000 Sydney ParaOlympics is further evidence of negative disability imagery being challenged and reconstructed in mainstream society. The disability movement is also encouraging the media and disability charities to contest misrepresentations and

negative campaigning and thereby dispel the myth that people with disabilities have little to contribute to society.

The discussion in this chapter now turns from issues of social embodiment to physical embodiment and how people cope physically and spatially with an impaired body.

PHYSICAL EMBODIMENT

A singular focus on representations of the body overlooks, Parr (1998) argues, 'the physical presence of the body ... of texture, smell and movement of bodies' (Parr, 1998:28). It is on these grounds that the social model of disability has been criticised for homogenising people with disabilities (Crow, 1996; French, 1994), leaving no space for individuals to recognise their physical limitations, to find self expression and celebrate their difference. This has led disability theorists to question the comprehensive nature of a model that fails to address differential experiences, interests and identities of people.

Voices of dissent began to emerge within the disability movement amongst feminist writers, who argued that their interests as women were not being addressed by the social model of disability (Begum, 1992; Morris, 1991, 1992, 1993). Just as it was feminist thinking that began to deconstruct the sex/gender divide, it has been disability feminists who have challenged the impairment/disability dualism. In both instances the women highlighted the importance of individuals' multiple identities and embodied experiences,

including those of impairment. As Morris (1991) writes, there is a tendency of the social model of disability,

> '... to deny the experience of our bodies, insisting that our physical differences and restrictions are *entirely* socially created. While environmental barriers and social attitudes are a crucial part of our experience of disability - and do indeed disable us - to suggest that this is all there is, is to deny the personal experience of physical restrictions ... of illness, of the fear of dying'.
>
> (Morris 1991:10).

Sensitivity, is therefore called for, to the tensions that exist between recognising 'that much of our experience of the body is socially constructed and our individual experiences of the physicality of our bodies and their strengths and weaknesses' (Butler & Bowlby 1997:415).

Finkelstein (1996) and Shakespeare (1992) oppose a move to acknowledge the limitations of impaired bodies. They argue that highlighting the pain and inconvenience caused by disabled bodies would be to take a retrograde step back into the medical model of disability and a re-emphasis on the biological body as a site of oppression rather than society as the site of oppression. As Shakespeare (1992) maintains '[t]he achievement of the disability movement has been to break the link between our bodies and our social situation and to focus on the real cause of disability, ie discrimination and prejudice. To mention biology, to admit pain, to confront our impairments, has been to risk the oppressors seizing our evidence that disability is 'really' about limitations after all' (Shakespeare, 1992:40; cited in Oliver, 1996:39).

The counter argument is put forward by Dorn (1998) who argues that we do not wish 'to exemplify a flight from the messiness of disability into myth and metaphor' (Dorn, 1998:184). This latter approach is gaining currency in the geographical literature (see Butler and Bowlby, 1997; Butler and Parr, 1999; Hall, 1999) and more generally in the disability literature (see Crow, 1996, French, 1994). Here it is argued that the limitations placed on the body by impairment have an undeniable role to play in the lives and living spaces of people with disabilities and that these factors are further exacerbated by the obstacles that society creates. 'If there is continued exclusion of the body, in all its flawed reality, from thinking about disability and health, then a whole area of issues of importance for the people affected will not be tackled' (Hall, 1999:25). To do otherwise, and to deny that an individual's embodiment, including their impairment, has no effect on their abilities and their geographies is a view which many people with disabilities cannot relate to (Butler and Bowlby, 1997). Crow (1996) is one such person, and she highlights the present theoretical crossroads within disability studies in the following quotations. In the first, she stresses the strengths of the social model, whilst in the second, she identifies its weaknesses.

> 'This was the explanation I had sought for years. Suddenly what I had always known, deep down, was confirmed. It wasn't my body that was responsible for all my difficulties, it was external factors, the barriers constructed by the society in which I live. I was being dis-abled – my capabilities and opportunities were being restricted – by prejudice, discrimination, inaccessible environments and inadequate support. Even more important, if all the problems had been created by society, then surely society could uncreate them. Revolutionary!'
>
> 'So how is it that, suddenly to me, for all its strengths and relevance, the social model doesn't seem so water-tight anymore? It is with trepidation that I criticise it. However, when personal experience no longer matches current explanations, then it is time to question afresh'.
>
> (Crow, 1996:207).

Living with Physical Impairment

It is the tensions between physical embodiment, social embodiment and disabling barriers in public spaces that I want to focus on next. To illustrate how physical embodiment impacts on the frequency with which people go out and their use of public spaces, including public toilets, irrespective of the presence or absence of disabling barriers.

> *With MS you'll find that an awful lot of people with MS, will say, I mean even if they're in a wheelchair, they can waken up in the morning and be lying in their bed, I'll just do this and I'll do this. And the next thing, the truth hits you slap bang in the face, you can't move, and it's not a nightmare, it's real life. And you have to, I mean what's the point in trying to fight it, I mean yes, you fight it to a certain extent, but be realistic. You know that's the only way, you can fight it in as much as your determination not just to buckle down and give in to try it again and be pleased that you've managed to do something positive, even if it's just cleaning your teeth. You know you've done it yourself, be proud of it, that's how you have to keep going. Really, the depression does hit you, I mean you've just got to accept it and let it wash over you, go through it and come out the other end, and say well that's that done with, and get on. ... I'm not saying I'm not sorry for myself, but again, I mean the frustrations and the anger are kept for myself and they build up and then all of a sudden I just explode. But I make sure I'm on my own, get it over and it's over and done with. That's it.*
>
> Gail, interviewed 6/2/97

> *The pain in arthritis is really, really bad, I mean there are days where I'm sitting and I just want a biscuit or something, you know my hands are like that and my elbows are in that position. He (husband) will say to me 'I'll feed you', and I'll go, 'Not feeding me', so I just dunna have it like.*
>
> Gillian, interviewed 12/2/97

The silence of the social sciences on physical impairment (Gleeson, 1999), has Crow (1996) claims made many of these things taboo. Yet, as Gail and Gillian illustrate, the pain and restrictions imposed on them by their physical impairments impacts on their lives, what they can do and where they can go.

Interviewees also found their geographies were circumscribed by their need to have someone with them at all times (see Dyck, 1995). As Gillian pointed out this also disables Philip, her full time carer and husband, by restricting where and when he can go out (see Milligan, 1997).

Interviewees emphasised they were fearful of going out alone, and it was apparent that this was related both to their (in)ability to manage their physical body independently in public space, coupled with their (lack of) confidence of moving in unfamiliar space. Thus, finding and using a public toilet is illustrative of the tensions inherent in the fear people with disabilities appeared to have of managing their physical impairment independently in public spaces, in addition to negotiating disabling barriers in public spaces. The availability and accessibility of public toilets was found to create a real concern for interviewees to the extent that it seemed to influence the frequency, distance and with whom interviewees were willing to venture into public space with.

> *As I say I refuse to travel away from Dundee and I won't go out anyway without anyone with me, it's a lot of different things, anxiety attacks, plus if I need the toilet, so anyway.*
>
> Ben, interviewed 9/1/97

Public toilets, Kitchin and Law (2001) argue, represent contemporary struggles over space, as they demonstrate how landscapes are constructed through particular power geometries. In their study on public toilets and people with disabilities in Ireland, Kitchin and Law (2001) concluded that insufficient and badly designed public toilets are limiting the use of space by people with disabilities and constraining them to particular patterns of spatial behaviour. In

the paper Kitchin and Law (2001) do not interrogate the question of physical embodiment, but concentrate on public toilets as a socially constructed disabling barrier. I want to extend the discussion, developed by the authors, to show how the physical body impacts on individuals spatial patterns and geographies. Interviewees stated that there were insufficient accessible public toilets in Dundee[2], yet many stressed that they were more apprehensive about their (in)ability to use a public convenience independently, than finding one in the first place. Thus, although the number of wheelchair accessible public toilets appears to be a problem with a social solution, an individual's ability and confidence to manage by themselves in public spaces and places is rooted in their physical embodiment, and their need for a full-time carer (Dyck, 1995).

> *If he (Philip, her husband) wasna driving I'd be lost. I've become so dependent now, even though I'm independent, you know what I mean? There's no way I could go out there and feel safe if I was on my own. I know in theory I could, I mean I have, but when I get back I feel so ill, so I just won't, I'd go with my daughter, go all the way down [town] in my wheelchair and get a taxi back. If I went out on my own, what if I needed to go the toilet, what if I really needed to go, there's always that nagging feeling, so you just don't go.*
>
> Gillian, interviewed 12/2/97

Gillian demonstrates that, like many interviewees, she sometimes *needs* her carer with her, whilst on other occasions she *wants* him with her, just in case she needs him. The problems encountered by people with disabilities in going out by themselves adds as a further dimension to understanding why interviewees who were living on their own went out less frequently than the other interviewees (see Chapter 6). Furthermore, it illustrates how the relationship between physical embodiment, social embodiment and disabling barriers is manifested in the spatial interactions of people with disabilities. The quotation below from Anna

captures the complexity of this relationship. Anna's mother is seen to be focusing on her daughter's physical needs, whilst Anna tries to transcend her physical body and begin to imagine where she could reasonably go in an electric wheelchair. The reality is Anna can't escape from her physical embodiment, the limitations that her impairment places on her body are a constant reminder of her positionality, and in this case her vulnerability as a wheelchair user in certain spaces.

> *Anna: No I don't think I'd go out on me own.*
> *Susan: No. Why is that?*
> *Betty: I don't think I could actually let her go out on her own, because if Anna's legs go into spasm, well her legs could come off the chair, and she has to have someone to put them back on. I'm not saying that would happen all the time, but just in case. She's never actually been out on her own.*
> *Anna: If I had an electric wheelchair for going outside, I could, but then, no, I won't go out coz you know with the gangs and that. The way they are here, I'd be thinking to myself they're going to pick me up, put me on the ground and be away with the chair.*
> *Susan: Does that frighten you?*
> *Anna: Yeah that's the way, you panic. I'd go out you know if somebody was with us, but not on me own, I'd be too frightened.*
>
> Anna, interviewed 31/1/97

Anna's ability to go out alone is a tangled web of body, chair and socially and spatially contingent factors. As Abberley (1987) contends, pain, fatigue and other symptoms of physical impairment 'are only ever apparent in a real social context' (Abberley, 1987:12). Hall (1999) calls for disability theory to move away from the dichotomous understandings of the body: medical versus social, biologically determinist versus social constructivist, as Abberley says to 'open up the space of the in-between' (Abberley, 1987:26) and combine biology and society. The body and impairment are to be rethought as a social-biological process or experience (Hall, 1999). So that the body is not clearly fixed as social

or physical, but is fluid, where the body is conceived as social, and social processes as part of the body or embodiment. 'The social context becomes an integral part of the experience of the biological process' (Hall, 1999:26).

CONCLUSION

'The whole of (social) space proceeds from the body'
(Lefebvre, 1991:405).

This chapter has concentrated on the body in an attempt to broaden the discussion on the experiences and geographies of people with disabilities. For the body is the unifying factor that draws all the chapters of this thesis together. To understand how different bodies are represented socio-culturally is to have a key to unlock the information on how spaces are produced as accessible or inaccessible for certain bodies. For bodies 'make and are made through the practices and geography of places' (Nast and Pile, 1998:5)

The social model of disability, coupled with a geographical imagination, provides a framework through which to explore how socio-cultural definitions of a deviant body configure themselves spatially. In the discussion on social embodiment, the negotiation of people's disabled identity and family and friends' perceptions of disability appeared to change over time. Prior to experiencing disability either first hand or through a friend or family member, disability was something that had rarely touched people's lives and where it had they had unconsciously reproduced ableist images of the disabled body. Thus it was

suggested that time, along with social and spatial factors, plays a significant role in influencing attitudes towards disability.

Drawing on insights from feminism and postmodernism disability geographers have criticised the social model of disability for narrowly focusing on physical and social disabling barriers and homogenising the experiences of people with disabilities in time and space. It has been shown that interviewees' geographies were delineated by the interplay between socially constructed barriers *and* their physical embodiment. People were apprehensive about venturing out into public space on their own for fear of not being able to negotiate unfamiliar and inaccessible spaces and/or being unable to meet their body's physical needs in public spaces. In other words, the physical body can and does constrain irrespective of physical and social barriers. The reintroduction of the physical body into debates on disability has exposed the tensions that exist between an individual's social embodiment of disability (the personal experience of living in a society that defines disability as abnormal) and physical embodiment (the constraints that physical impairment imposes on the body); and how the two interact spatially.

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[1] CandoCo dance company was founded in 1991 as Britain's first 'integrated' dance company, with three wheelchair users and five able-bodied members. Celeste Dandeker says about the group, 'I hope that people forget about the wheelchairs when we perform, and concentrate on the dance'. This practical commitment to turning disability first into something positive and, ultimately, into something audiences don't even notice lies behind her philosophy (Stanford, 1998:29).

[2] Not only did interviewees note that there were insufficient accessible public toilets in Dundee, but that many had 'special' conditions attached to them, like acquiring a key from the council to access the toilets out of working hours.

8

CONCLUSION

INTRODUCTION

This thesis has examined the experiences of people with disabilities living in different types and tenancies of housing across the city of Dundee and has identified the physical and social barriers associated with their housing and living spaces. Their experiences have demonstrated that people with disabilities feel both physically and socially marginalised and excluded from participating fully in society. The social model of disability and a discourse of ableism have framed the interpretation of the data as well as the reasons as to why barriers persist and why disabled bodies are perceived, socio-culturally, to be deviant.

The thesis has privileged the voices of the Other as a valid way of knowing. It has used the words of the interviewees as a guide to the structure and content of the arguments on how ableism has shaped individual experiences of disability, subjective identities and spatial interactions. The inaccessibility of mainstream housing and, paradoxically, the accessibility of special needs housing, along with the availability and utilisation of housing knowledge, were used as examples of spatial and social manifestations of ableism, which construct real and imaginary boundaries to the exclusion of people with disabilities. It was suggested that a more reciprocal dialogue is required between service providers and service users to give people with disabilities more choice and ownership over their housing decisions and to broaden the knowledge base from which service providers work.

DIFFERENCE

> 'If one was to try to identify a single theme that resonates throughout intellectual and political debates in the 20th century it might well be 'the difference that difference makes''.
>
> (Chouinard, 1997:379).

The concept of difference is a key theme that has threaded its way through the research process from the initial choice of subject matter to its conclusion. It is for this reason that this final chapter is divided into four sections each highlighting how the study contributes to knowledge on the geography of difference. First, it highlights the difference disability makes to the lives of people with disabilities and secondly, the differences between the disabled themselves. Thirdly, the chapter considers calls in the disability literature for emancipatory research to empower people with disabilities to make a difference to their lives through resisting ableism. Finally, I conclude the chapter by suggesting alternative ways that research can challenge ableism and address a constant refrain made by interviewees that, the able-bodied do not understand what it means to be disabled, to be different and consequently excluded by physical and social barriers in their living spaces.

Disability Makes a Difference

Disability has been exposed as making a difference to how social space is experienced and interpreted by people with disabilities. In the following section I want to highlight the ways that disability has been shown to be produced by ableism and public policies at the scales of the body, home and neighbourhood. Discussion in Chapter 7 focused exclusively on the body, demonstrating that the

way individuals negotiate their social embodiment is influenced by socio-cultural representations of deviant bodies. The extent to which people accept or resist a disabled identity was shown to have repercussions on their interactions in public space. At the scale of the home, Chapter 4 outlined the development of special needs housing, which has paralleled the growing realisation at government level that, people with disabilities have different housing needs from the rest of the population. However, it was argued that building only small numbers of accessible housing has meant that the bulk of the housing stock remains inaccessible to wheelchair users. Consequently, the inaccessibility of mainstream housing (along with many shops, offices and other public buildings) was seen to be curtailing the geographies of people with disabilities by restricting their ability to enter and socialise in many of the spaces that able-bodied people use in their day-to-day lives. Thus the construction and configuration of the built environment can be seen as disabling, as creating insurmountable barriers for wheelchair users that restricts their movements in public spaces.

Chapter 5 introduced social barriers into the discussion of how and why disability makes a difference to people's lives. In so doing it broadened the focus of investigation from the home to the social interaction occurring between people with disabilities and their neighbours. Attention focused on insiders (people with disabilities living in sheltered housing) and their perceptions of their social interactions with their older neighbours. Insiders suggested they were finding it difficult to feel included in social activities that were designed for the majority population (older people) within sheltered housing schemes. This left

people with disabilities feeling isolated and excluded in spaces that housing providers had deemed suitable for them.

Differences Between People with Disabilities

As this study progressed, the notion of a homogeneous, essentialist view of people with disabilities appeared increasingly incongruous. The findings of the research demonstrate that people with disabilities are a heterogeneous group of people differentiated by the characteristics of tenancy, household size, house type and physical impairment. I want to consider the saliency of these differences as they emerged from the data in relation to the scales of the body, the home and the neighbourhood (place).

The physical body was introduced into Chapter 7 in order first, to distinguish the constraints imposed on people with disabilities by society from those that they experience through living with a physical impairment, and secondly, to begin to understand how different impairments impact on people's spatial interactions, irrespective of social and physical disabling barriers.

Chapter 4 demonstrated that developments in the design and provision of wheelchair accessible housing in Dundee is enhancing the independence and quality of life for people with disabilities. However, it was noted that whilst this type of housing is recognition of the differences between the disabled and able-bodied, it fails to recognise differences between people with disabilities. Consequently certain design features in special needs housing were exposed as

insensitive and as standardising the range of needs of this section of the population. In particular, the design of ostensibly accessible kitchens was seen as inflexible and unable to accommodate the different needs of both the disabled and able-bodied.

The adoption, in this study, of a holistic approach to the housing of people with disabilities, beyond that of bricks and mortar, has revealed how different places can disable and/or enable people to function in frictionless living spaces. This was demonstrated by using the concept of place in two contrasting ways, first, as physical, 'bounded space' and second as social, 'constructed space'. According to humanistic geographers bounded space provokes particular sets of feelings, emotions and attachments. For example, the neighbourhood was used in Chapter 6 to illustrate the importance of place to individual preferences with regard to moving house or staying put. Owner occupiers appeared to have a stronger attachment to their house and neighbourhood than social housing tenants. Owner occupiers contentment with their housing seemed to be related to their greater ability to control and shape their living space to their own requirements. This finding does, however, raise important questions as to why the social renters were keen to move, even when they lived in a well-designed, accessible house. Location was also shown to influence whether people were 'locked in place' by the inaccessibility of their neighbourhood, including shops and the houses of family and friends. This appeared to apply more to the lives of people who lived alone and didn't have a car, than to those living with a full time carer who had a car which enabled them to transcend the boundaries of place (Chapter 6).

Secondly, place was problematised by demonstrating that places are not only defined by fixed, identifiable boundaries and characteristics, but are constructed by relationships of power that are fluid and responsive to societal changes and imagery. The example of sheltered housing (Chapter 5) illustrated the conflicting interpretations of places held by insiders and outsiders, and how boundaries convey different meanings to people depending on individual relationships to places. Furthermore, Chapter 5 demonstrated how the conflicting interpretations of place held by insiders and outsiders, influences the way identities are constituted in place, and thus the importance of place in the negotiation of social embodiment.

In an increasingly shrinking and similar world, the differences between places retains the interest and the preserve of geographers. Certainly the importance of place in shaping the lifeworlds of people with disabilities, is a stark reminder that place matters, and understanding the power relations that make place matter is a crucial task for geographers. Housing providers should also pay heed to the importance of place in housing allocations, and be sensitive to how different places can enable and/or disable people with disabilities.

Making a Difference

The growing interest in disability issues in academia and public policy is recognition that people with disabilities are becoming more visible and vocal in society. The Disability Discrimination Act, amendments to Part T of the building regulations and recent social inclusion policy initiatives can all be seen

to be a reflection of the impact of recent social theorising on disability as it filters into the thinking that informs public policies and society's attitudes. This alone must surely be seen as making a difference to the lives of people with disabilities. Furthermore, the discourse of the social model of disability increasingly informs the conditions that major funding bodies attach to research on disability issues (Oliver, 1997). For example, the Joseph Rowntree Foundation established its Disability Committee in 1988, and has subsequently been committed to consulting people with disabilities and to funding research which is designed to develop initiatives that people with disabilities themselves think are important. The following are the specific requirements the foundation attaches to research overseen by the 'Social Care and Disability Committee':

- All projects should be located in, or draw upon, the social model of disability or other social models.
- We are interested in projects that identify, challenge and remove barriers to social inclusion, where barriers are located in society, services, policy and practice; and where people (children, adults, their families) are 'socially excluded' because of impairment, old age, support needs, disabling barriers, racism, etc.

(JRF, 2001).

However, over the last decade disability researchers have begun to stretch the boundaries of what disability research can hope to achieve and question whether academics can successfully move beyond pure 'investigation' into praxis and 'production' (Oliver, 1999). Where 'investigation' refers to the established research process of creating and presenting/publishing new knowledge, and 'production' refers to emancipatory research that seeks explicitly to produce social change and make a difference to the lives of people with disabilities.

Although this study was not designed to be emanicpatory, it was decided to provide the interviewees with a summary report of the research findings (Levy, 2000, Appendix E). There were two objectives in sending the report to interviewees, first, to enable them to read about the experiences of other people with disabilities and possibly see similarities between their experiences and others, and secondly, as a form of empowerment: to help people realise that their voices are important. The report was also sent to stakeholders, including Scottish Homes, the Scottish Executive and people working on the ground in the allocation and provision of housing for people with disabilities in Dundee. The objective here was to create a channel for conveying the findings of the study to the people who, using a traditional understanding of power, have 'power over' the housing outcomes of people with disabilities. All the recipients of the report were asked to forward their comments on the findings to me. This was the email response that I received from Ben:

> *The report was very constructive, and knowing the quotes were from real people with real problems had a real impact on the issues being addressed, (I thought). It would be great to think that the service providers will take note of the problems being faced in day to day living by people with varying disabilities and incorporate some of the ideas into any new developments. But I won't hold my breath, as we all know it all boils down to funds and resources.*
> *I spotted my own quotes straight away when reading through the report, Ben, a nice choice of pseudonym, thank you. Though I might of picked something a bit more butch myself (laughing)!*
>
> Ben, email correspondence 7/4/00

Ben was the only interviewee to respond to the report, and his response raises a number of pertinent questions particularly with regard to the feasibility of conducting emancipatory research. First, how accessible is the research process for non-academics? My intention in writing the summary report was to create a

document that would be accessible to interviewees and stakeholders. Did the style of the report, which included tables and some theoretical and methodological jargon, deter the interviewees from commenting on it? Secondly, to what extent do people with disabilities want to take an active role in the research process? There is a de facto assumption made by advocates of emancipatory research that Other people have an interest in the research process. Perhaps the single response to the report from the interviewees suggests that whilst they agreed to be interviewed, and may even have found it a cathartic experience, they did not want to take a more active role in the research process beyond that of communicating their experiences to me. Alternatively, it possibly says something about the immediacy of the research process, the need to involve people in a continuous process and not one that is stretched over a number of years (three years elapsed between the interviews and the production of the report). I do not have answers to these questions but raise them as caveats, as a call for caution in making assumptions about the involvement of Others in the research process.

The response to the report from stakeholders was slightly more encouraging, 7 out of 20 (35%) replied, with a number of requests for additional reports. A mini-questionnaire (Appendix C) was enclosed with the report sent to stakeholders to structure and focus agency's responses to the study. This was done in the belief that it would increase the number of agencies that would forward comments on the report to me. (The very low response rate of interviewees may be indicative of my failure to send them a similar questionnaire to guide their responses). Overall the comments of stakeholders on the report fell

into three main categories. first, there were remarks like Ben's, that referred to a lack of resources as the main stumbling block to adopting a more holistic and sensitive approach to the housing needs of people with disabilities. Secondly, there were responses that called for the study to be contextualised in relation to mainstream housing needs, and finally, in contrast, there were comments that suggested that the study was too wide ranging to be relevant to an agency's specialised service.

When I received these responses, I questioned whether the respondents had grasped the fundamental message that the report was intended to convey: of the power of ableist attitudes and practices to exclude and marginalise people with disabilities at all levels within society. References to a lack of resources, or the applicability of the study to specific groups of people, are relevant comments that require attention, but they need to be tackled in parallel with challenging and changing ingrained perceptions and attitudes of disability and disabled bodies. It is perhaps a weakness of this research that time constraints prevented me from discussing the study findings face-to-face with service providers. I acknowledge that further contact with the people who influence control and have 'power over' the housing of people with disabilities could well have helped to address Helen's concern that:

> *... you've first of all got to break down the barriers and make them (statutory agencies) realise that you're not just a name on a piece of paper, you're a person.*
>
> Helen, interviewed 6/2/97

Helen's disquiet also raises, I believe, a more fundamental issue, which is: situating studies in the margins and researching the Other uncovers what is

happening in the centre (Jackson, 2000) through highlighting the hierarchical nature of the relationship between the centre and the margins. In other words, the powerlessness and oppression experienced by people with disabilities is exposed as emanating from policies and practices situated in the centre. Thus, it is not just the perceptions of the people who have 'power over' the disabled, but the attitudes and perceptions of the able-bodied more generally that need to be disrupted.

Understanding and Challenging Disability

By reflecting on the responses I received on the summary report and building on my experience more generally of conducting my doctoral research, I want to suggest that disability research must make space for researching the able-bodied, to make a difference to how the able-bodied perceive differences in and between social groups. A clear and repeated message that emerged from the interviews was for the able-bodied to learn more about disability and being disabled. To be given an insight into what it means to live on the margins, in a body that is perceived to be abnormal, and how ableist attitudes, consciously or unconsciously, produce spaces that marginalise and exclude people with disabilities. Interviewees frequently referred to feeling misunderstood and that their needs were unmet because service providers and society generally did not understand what it meant to be disabled. The potential implications of this learning process are immense for challenging the hegemony of ableism and empowering people with disabilities. I argue that investigating the able-bodied and seeking to unsettle and challenge their perceptions of disability is a potentially new field of study for disability researchers to consider. This

suggestion is empirically based in interviewees feelings of being misunderstood and their experiences, along with those of their family and friends', that, perceptions of difference are social constructed and can therefore change over time.

I acknowledge that, (unconsciously), I set out at the start of this study, being guided and often blinded by ableist assumptions. I wasn't aware of the physical and social barriers in my living spaces, if they didn't impact on my life. This study has led me to the conclusion that my experience is not particularly unique for an able-bodied person. 'It is the fact that exclusions take place routinely, without most people noticing, which is a particularly important aspect of the problem' (Sibley, 1995:xiv). Barnes (1992) reiterates this point by stating that, although he has been physically impaired all his life, it wasn't until he began researching other people with disabilities that he realised 'the extent of institutional discrimination against disabled people' (Barnes, 1992:121). During the course of the study my ableist assumptions have been radically challenged and changed, so that at the end of the study, my positionality has been altered through confronting my background and viewing the world anew. My experience in the field is illustrative of the politics of difference, and the power of social and spatial factors to influence who and how we define people as different. It also demonstrates that researchers are a research tool, in so far as their positionality can be altered during fieldwork with subsequent implications for the direction of the research. As Smith (1988:27) claims, simply by being in the field, the researcher can influence the kinds of things that people say and do, '... my impression at the end of two years fieldwork is that *I* changed. ... For the

analyst's self is not a coherent static assemblage of personality traits that is able to observe without absorbing'. Smith, however, fails to note that if, during the period of fieldwork, she as a researcher is capable of change, so too are the researched. This is now a central objective of emancipatory research, that people learn to renegotiate their identities through self understanding during the research process. Oliver (1992) has emphasised the need for disability research to engage with the able-bodied, arguing,

> 'it is not disabled people who need to be examined but able-bodied society; ... the disableism ingrained in the individualistic consciousness and institutionalised practices of what is, ultimately, a disableist society' (Oliver, 1992:112).

Research that seeks to challenge established mind sets and understandings of how society unjustly treats certain groups of people based on their bodily difference requires the boundaries between the spaces of the margins and the centre to be porous: to allow the margins into the centre and draw people into a 'third space' where identities can be renegotiated.

A geography can thus be seen to be emerging in relation to geographical research on disability: between studies that are conducted in and research the margins, and those that are potentially situated in the centre. Current disability studies that have investigated and worked towards the empowerment of people with disabilities have focused on the geographies of the margins, that is *empowering* the *margins*. I suggest there is scope for including studies that could complement current research objectives by seeking to investigate and work towards changing ableist attitudes and the perceptions of able-bodied people situated within the centre, in other words *change* the *centre* (Table 8.1).

Table 8.1 Approaches to Studying Disability

Time	Theory	Method*	Geography
Current	Socio-spatial construction of disability	'Investigation' of new knowledge	Margins
Current	Socio-spatial construction of disability	'Production' to change established knowledges	Margins
Future	Socio-spatial construction of disability	'Investigation' of new knowledge	Centre
Future	Socio-spatial construction of disability	'Production' to change established knowledges	Centre

*'Investigation' and 'production' are borrowed from Oliver (1999), as discussed above, to define the two different methods.

CONCLUSION

The transformative potential of disability, to disrupt how people think about the world and the spaces we live in, is only beginning to be realised through research and structural changes to the built environment. Historically the design of the built environment restricted people with disabilities to 'special' spatially accessible places, and conveyed the message that they were unwelcome in the spaces of the able-bodied. The inaccessibility of space and place helped to reproduce binary divisions between the able-bodied and disabled, the same and Other, the normal and abnormal. In addition, it helped disabled and able-bodied people 'to know their place' in society. Recent legislation requiring all new public and private buildings to be constructed to barrier free standards will draw the disabled (Other) and the able-bodied (same) into ever greater contact, and potentially disrupt these dualisms. The future at the start of the twenty-first century, where boundaries and identities are porous and not fixed, less clear cut

and predictable, is uncertain, only time will tell whether structural changes can influence socio-cultural perceptions and practices and allow the Other into the spaces of the same. This is a challenge for future geographical studies on disability.

APPENDIX A

SOCIO-DEMOGRAPHIC BACKGROUND OF INTERVIEWEES

Alex

Interviewed 9/12/96 and 11/4/97. Alex aged 31, is a social housing tenant and was living with her sister when I interviewed her. In our first interview Alex was living in an unadapted two storey flat on the 14th floor of a tower block. When she moved into a purpose built flat she invited me to see and talk about her new accommodation. She uses her wheelchair all the time.

Alice

Interviewed 14/1/97. Alice, a 50 year old permanent wheelchair user, was living with her sister when I met her. Alice and her sister were hoping to move out of their adapted council flat into sheltered housing.

Amy

Interviewed 12/2/97. Amy, a 40 year old mother of one, was living with her husband and young son in their owner occupied, two storey house. They had adapted the house to meet the family's needs. Amy uses her wheelchair all the time.

Angus

Interviewed 22/1/97. Angus is 62 years old and married. He was living with his wife in an adapted, ground floor flat when I met him. He is a permanent wheelchair user.

Anna

Interviewed 31/1/97. Anna was 23 years old when I met her, she and her brother lived with their mother in her owner occupied, two-storey home. The family home had been extended to accommodate Anna's changing needs, as she now needs to use a wheelchair all the time.

Ben

Interviewed 9/1/97. Ben, 31 years old, was living alone in his ground floor flat in a sheltered housing scheme when I interviewed him. He is an infrequent wheelchair user.

Beth

Interviewed 6/6/97. Beth, a 46 year old single woman, was living in her owner occupied ground floor flat, that she had adapted, when I met her. Beth is a permanent wheelchair user.

Beverley

Interviewed 18/2/97. Beverley, a 59 year old divorcee, lives alone in a sheltered housing scheme. She uses her wheelchair most of the time.

Catherine

Interviewed 26/2/97. Catherine, aged 30, is married and lives with her husband and daughter in a sheltered housing scheme. She uses her wheelchair at all times.

Chris

Interviewed 12/3/97. Chris was aged 63 years when I interviewed him in his owner occupied home, where he lives with his wife. Chris is an infrequent wheelchair user.

Deborah

Interviewed 20/1/97. Deborah, aged 54, lives with her mother in a sheltered housing scheme. Deborah uses her wheelchair all the time.

Donald

Interviewed 19/2/97. Donald, aged 63, lives alone in a sheltered housing scheme. He uses his wheelchair all the time.

Duncan

Interviewed 5/2/97. Duncan, aged 47, was living in a purpose built housing association dwelling, with his mother when I interviewed him. He is a permanent wheelchair user.

Emma

Interviewed 26/3/97. Emma, aged 64 years, is a home owner, and was living in her adapted, two-storey house when I met her. She lives with her 26 year old daughter, and she is an infrequent wheelchair user.

Ester

Interviewed 23/1/97. Ester, aged 26, was living with her parents in a purpose built wheelchair house, owned by a housing association. Ester uses her wheelchair all the time.

Gail

Interviewed 30/1/97 and 6/2/97. Gail was 50 years old when I met her, she lives with her husband in their adapted, owner occupied, two-storey house. At the end of our first meeting Gail suggested that I came back and she would give me a copy of a report on community care that she had been involved in presenting at a

conference. When I returned we continued talking and I taped our conversation as a second interview. Gail is a permanent wheelchair user

Gerry

Interviewed 17/1/97. Gerry, aged 61, is single and was living in a sheltered housing scheme when I met him. He uses his wheelchair all the time.

Gillian

Interviewed 12/2/97. Gillian was 37 when I met her and her husband (her full time carer). She lives in a sheltered housing scheme with her husband and three children. Gillian uses her wheelchair all the time.

Hannah

Interviewed 11/12/96. Hannah, aged 62, lived with her husband in a housing association property that had been built to wheelchair accessible standards. Hannah uses her wheelchair all the time.

Helen

Interviewed 6/2/97. Helen, aged 35, was living alone in a sheltered housing scheme when I met her. She needs to use her wheelchair all the time.

Ian

Interviewed 11/2/97. Ian was a 60 year old permanent wheelchair user when I interviewed him. He was a home owner and lived in the family home with his wife, who was his full time carer.

Irene

Interviewed 25/2/97. Irene, aged 59, lives in a purpose built, housing association dwelling. She was living with her husband and 28 year old son. She was an infrequent wheelchair user when I interviewed her.

Iris

Interviewed 28/1/97. Iris, aged 62, lives in her ground floor flat with her husband. They owned the flat which they have had adapted to meet Iris's needs. Iris uses her wheelchair at all times.

James

Interviewed 14/1/97. James, aged 52, was living on his own in a sheltered housing scheme. He uses his wheelchair all at times.

Jim

Interviewed 27/2/97. Jim, aged 59, was a divorcee now living alone in a sheltered housing scheme. He always uses his wheelchair.

John

Interviewed 6/3/97. John, aged 57, lived with his wife in a purpose built house which they owned. John uses his wheelchair at all times.

Julie

Interviewed 13/3/01. Julie was a 35 year old mother with a 6 year old daughter when I met her. She lived in the family, owner occupied home with her husband and daughter. The two-storey house had been adapted to meet Julie's needs as an infrequent wheelchair user.

Kevin

Interviewed 2/4/97. Kevin lives with his parents in the family, owner occupied home. He was 32 when I interviewed him, and he uses his wheelchair all the time.

Laura

Interviewed 23/1/97. Laura, aged 61, who worked full time as a teacher before retiring, lived with her husband in their owner occupied, purpose built house. Laura uses her wheelchair at all times.

Liz

Interviewed 13/3/97. Liz, aged 31, was living with her boyfriend and studying part time when I met her. She was living in a purpose built flat, and used her wheelchair infrequently.

Lucy

Interviewed 24/1/97. Lucy, aged 63, was living with her husband in a purpose built house. She uses her wheelchair most of the time.

Marina

Interviewed 20/2/97. Marina, aged 59, lives with her ex-husband, now her carer, in a sheltered housing scheme. She has to use her wheelchair all the time.

Mark

Interviewed 11/2/97. Mark, aged 18, was living with his parents and sister in the family home. The house was a purpose built, housing association property. Mark uses his wheelchair outside but not inside the house.

Maureen

Interviewed 6/3/97. Maureen, aged 56, was living with her husband in their unadapted council house when I interviewed her. She needs to use her wheelchair all the time.

Megan

Interviewed 28/1/97. Megan, aged 63, works part time for a disability charity, and lives with her husband and 26 year old daughter in their purpose built housing association house. She uses her wheelchair all the time.

Morag

Interviewed 21/1/97. Morag, aged 54, was living in an unadapted, ground floor council flat with her husband, when I met her. Morag needs to use her wheelchair most of the time.

Neil

Interviewed 3/2/97. Neil, aged 33, had returned to live with his parents in their owner occupied property until he found a suitable house that could accommodate his changing health needs. He is an infrequent wheelchair user.

Pat

Interviewed 27/5/97. Pat, aged 50, lives by herself in a purpose built housing association house. She uses her wheelchair all the time.

Penny

Interviewed 5/2/97. Penny, aged 39, was living with her husband and four sons when I interviewed her in their two-storey, council house. Penny is an infrequent wheelchair user.

Robert

Interviewed 6/2/97. Robert, aged 53, was living with his wife in a sheltered housing scheme when I interviewed him. He needs to use his wheelchair all the time.

Rose

Interviewed 13/2/97. Rose was 43 years old and living with her husband. They were social housing tenants living an adapted house. She was a permanent wheelchair user.

Ryan

Interviewed 22/1/97. Ryan, aged 64, was living with his wife in a sheltered housing scheme. He uses his wheelchair all the time.

Sally

Interviewed 16/1/97. Sally, aged 24, lives by herself in a sheltered housing scheme. She needs to use her wheelchair all the time.

Sara

Interviewed 25/3/97. Sara was aged 53 years when I interviewed her. She uses her wheelchair all the time and has adapted the family home that she and her husband own.

Simon

Interviewed 26/3/97. Simon aged 55 years, is an infrequent wheelchair user. He lives with his wife in their owner occupied, adapted house.

Ted

Interviewed 11/3/97. Ted aged 64 was living alone in his ground floor council flat, that had been adapted. He used his wheelchair at all times.

Thomas

Interviewed 5/3/97. Thomas, aged 58, lived with his wife in their two-storey house. The house was on the market and the couple were keen to move into a more accessible property. Thomas needed to use his wheelchair at all times.

Tom

Interviewed 24/4/97. Tom was 42 years old when I interviewed him in his owner occupied, adapted house. He lives with his wife and two young daughters. He needs to use his wheelchair all the time.

Zoe

Interviewed 8/12/96. Zoe, aged 48, was living in her family home with her mother, sister and niece. The house was owned by her mother and had been adapted to meet Zoe's needs, by the installation of a through-the-floor lift. Zoe needed to use her wheelchair at all times.

APPENDIX B

DEFINITIONS OF:

- SPECIAL NEEDS HOUSING
- BARRIER FREE STANDARDS
- LIFETIME HOMES STANDARDS

SPECIAL NEEDS HOUSING

ADAPTED HOUSING

Dwelling that has been altered to make it more suitable for people with disabilities, including structural alterations ie extension to develop ground floor bedroom and/or shower room, or less intrusive adaptations such as stair lift or ramped entrance.

AMBULANT DISABLED HOUSING*

Part 6 of the 'Scottish Housing Handbook: Housing for the Disabled' (1980), recognised that not all people with disabilities required fully wheelchair accessible housing. It is similar to mobility housing (the term used in England). Ambulant disabled housing included the following features:

- Access to the front door in the form of a ramp, or level access.
- A minimum width of 900mm for corridors and doors.
- In the case of a two-storey house, the use of a plan which would allow a stair lift to be fitted.

AMENITY HOUSING*

Part 5 of the 'Scottish Housing Handbook: Housing for the Elderly' (1980), recognised the need for housing many elderly people which fell between small mainstream houses and sheltered housing. Amenity housing served to fill this gap and incorporated:

- Whole house heating.
- Grab rails and special bathroom fittings.
- No call system or warden service.

MOBILITY HOUSING*

Mobility housing is the English equivalent of ambulant disabled housing. Details of mobility housing are outlined in Dept. of Environment Circular 74/74, para. 12. Two criteria were used to differentiate mobility housing from mainstream housing, they were:

- The approach to the house had to be level or ramped.
- The doorways to principal living areas and bedrooms had to be at least 900mm.

PURPOSE BUILT WHEELCHAIR HOUSE

Part 6 of the 'Scottish Housing Handbook: Housing for the Disabled' (1980), details the design of dwellings to 'livability' standards, which includes extra circulation space, providing wheelchair users with full access throughout the house, including lowered working surfaces in the kitchen, and fully accessible bath/shower-room.

SHELTERED HOUSING

'Housing specially designed for elderly people grouped together with a range of communal facilities' (National Housing Federation, 1997:142).

SUPPORTED HOUSING
'Shared or self-contained accommodation in which older people or residents with special needs are provided with a wider range of services designed to meet their needs' (National Housing Federation, 1997:151).

* These terms have now been replaced with Barrier Free Standards in Scotland and Lifetime Homes Standards in England (Walker, 2001).

BARRIER FREE STANDARDS

Internally

1. Circulation areas are at least 900mm, preferably 1000mm, wide, unobstructed by fittings and allow a wheelchair user to enter the essential rooms.
2. All pass doors have a clear width of at least 750mm and are hinged to allow easy circulation.
3. In 2 storey houses the staircase could take a lift or the floor plan allows for a through-floor lift to be installed.
4. Room sizes in general allow for adequate space for circulation and at least one bedroom allows for a wheelchair to go alongside the bed.
5. The kitchen is designed with a continuous worktop between hob and sink and with a space of at least 1200mm in front of the fittings.
6. The bathroom is accessible in a wheelchair and can accommodate either or both a bath and/or walk-in shower.
7. Any WC at entrance level is accessible in a wheelchair.
8. Window ironmongery, in terms of opening gear, handles and safety catches, has been selected for ease of operation, cleaning and security.
9. Door handles are easy to grasp and operate (lever type) and are fitter 900-1050mm above floor level.
10. Light switches are of pad or rocker type and located at door handle height, 900-1050mm above floor level.
11. Power sockets are situated at a minimum height of 450mm above floor level.
12. Heating controls, radiator controls, meters, main switches and fuse boxes are easily accessed, reached and operated.

It is also desirable that:

- Living room windows allow a seated person to see the view outside.
- Tap heads are crosshead or lever type.

Externally

13. The entrance is step free, with no slope greater than 1:12, a level area at the door and a threshold that can be negotiated in a wheelchair;

or,

entrance steps have a rise of no more than 150mm and a going no less than 320mm, have a handrail and there is space for the steps to be replaced or supplemented with a ramp if need.

14. Entrance doors, including those to common access areas, have a clear opening width of at least 775mm.
15. Lifts are accessible to wheelchair users with,
- the path from the road to the lift free of steps,
- lift doors are at least 750mm wide;
- internal dimensions of at least 1200mm deep and 1100mm wide;
- landing area on each floor at least 1500X1500mm;
- lift controls at a height of no more than 1200mm from the ground and usable by people with impaired sight.
16. Pathway from road and car space to entrance is free of steps and any gate has clear opening of at least 850mm.
17. Door entry systems and door bells are at a height of no more than 1200mm from the ground.
18. Signage, including house numbers, is designed to be easily read.

It is also desirable that :-

- Common access stairs have a pitch of approximately 35 degrees or less and have highlighted nosings.
- Bin store and drying area have step free access by a path at least 900mm wide.
- Parking, (or garage or car-port), is within the curtilage or there is a designated parking space within 30 metres of the entrance.
- Surrounding paths and roads allow for the mobility of disabled people.

Scottish Homes, 1995 *The Design of Barrier Free Housing*

LIFETIME HOMES STANDARDS

1. Parking space capable of enlargement to 3.6m.
2. Minimum distance from parking space; level or gently sloping.
3. Approach to the entrance to be level or gently sloping.
4. Lifts to be wheelchair accessible.
5. Entrances covered and illuminated; level access over thresholds.
6. Widths of doorways/hallways in accord with the Access Committee for England's standards.
7. Wheelchair turning circle (1500mm width) in all ground floor rooms.
8. Wheelchair accessible downstairs toilet, plus opportunity for shower later.
9. Living room at entrance level.
10. Walls in bathrooms and toilets able to take hand-rails.
11. Ground-floor bedspace in two-storey houses.
12. Bath/bedroom ceiling strong enough for hoist; removable door panel between bath/bedroom.
13. Provision for future stair/chairlift; joists trimmed for through-the-floor lift.
14. Accessible basin, WC and bath.
15. Window-sills usually 750mm or lower and windows easy to open/operate.
16. Switches, sockets, controls etc. at a height of 600-1200mm.

(JRF, 1997b)

APPENDIX C

QUESTIONNAIRES

- INTERVIEW QUESTIONNAIRE
- MINI QUESTIONNAIRE SENT TO STAKEHOLDERS WITH SUMMARY REPORT

School of Geography and Geosciences
University of St Andrews

QUESTIONNAIRE:

WHEELCHAIR USERS AND HOUSING IN DUNDEE

Name

Ref. No.

House type

Interview Date

Interview start/finish time

ABOUT YOURSELF

1. DOB .....

2. Sex O Male O Female

3. Marital Status O Single O Married O Divorced/widowed
O Widowed O Living with Partner

4. Employment O Paid work O Voluntary work O Retired
O Studying O Housewife/husband O Other

5. Are you in receipt of state benefits? OYes O No

If yes, which benefits? .....

6. Family income O <£4,999 O £5,000-£9,999 O £10,000 - £14,999
O £15,000 - £19,999 O £20,000 - £24,999
O £25,000 - £29,999 O > £30,000 O No reply

7. Ethnic origin O White (UK/Irish) O White (Other) O Indian
O Pakistani O Black African OBlack Caribbean
O Chinese O Asian (Non Chinese) O Other

8. No. living in household .....

9. Formal carers O Nurse O Home help O Personal assistant
O Other.....

10. Wheelchair use:

Inside: O Always O Frequently O Infrequently O Never

Outside: O Always O Frequently O Infrequently O Never

11. Length of time using wheelchair

O < 1 yr. O 1- 4 yrs. O 5 - 9 yrs. O All of life

12. Wheelchair types

O Powered indoor/outdoor O Powered indoor O Powered outdoor

O Manual O Scooter

ABOUT YOUR HOUSE

13. Tenancy

O LA tenant O HA tenant O SH tenant O Shared ownership

O Owner occupier O Private tenant OLiving with parents

14. Length of time in house

O < 1 yr. O 1- 4 yrs. O 5 - 9 yrs. O > 10 yrs.

15. House type

A. O Adapted mainstream O Unadapted mainstream

O Sheltered O Purpose built

B. O House > 1 floor O House with ground floor only

O Flat, ground floor O Flat, upper level

16. Entrance to house

O Level access O Ramp O Steps O Lift

17. Adaptations and features in house

General Features	✔	***Bathroom***	✔
Wide door frames		Downstairs bathroom	
Raised sockets		Walk-in shower	
Accessible door handles		Grab rails - toilet	
Accessible light switches		Grab rails - bath	
Central heating		Hoist over bath	
Double glazing		Adapted toilet	
Open windows		***Bedroom***	
See out of windows		Downstairs bedroom	
Stair lift		Ceiling hoist	
Through floor lift		***Outside***	
Community alarm		Parking space by house	
Kitchen		Accessible driveway	
Lowered work surface		Dropped kerb by house	
Accessible sink/taps		Accessible garden	
Accessible hob/oven		Accessible local shops	

18. Service providers - main contact .....

Helpfulness O Very helpful O Helpful O Neutral

O Unhelpful O Very unhelpful

19. Accessibility of housing information

O Very easy O Easy O Neutral

O Difficult O Very difficult

20. Importance of being involved in housing decisions

O Very important O Important O Neutral

O Unimportant O Very unimportant

21. Feel involved in housing decisions

O Yes O No ODon't know

22. Preference to adapt/move house

O Move house O Adapt house O Don't know

23. Length of time to wait to move/adapt house .....

24. Would like to live in sheltered/disabled housing scheme

O Yes O No O Don't know

25. Satisfaction with house

O Very satisfied O Satisfied O Neutral

O Dissatisfied O Very dissatisfied

ABOUT YOUR NEIGHBOURHOOD

26. Live in supportive neighbourhood

O Yes O No O Don't know

27. Main obstacles in neighbourhood .....

28. Importance of local shops

O Very important O Important O Neutral

O Unimportant O Very unimportant

29. Frequency going out O Daily O > once a week O Once a week

O < once a week O < once a month

30. Car in household O Yes O No

Addressing the housing needs of people with disabilities: social inclusion through empowerment

Susan Levy
University of St Andrews

Thank you for reading the report, I would appreciate you spending a few minutes commenting on the findings. Please answer all questions and feel free to continue your comments on the back of the questionnaire or on an additional sheet of paper. Please return the completed questionnaire in the enclosed sae by Friday 28 April 2000.

For questions 1 to 4 please indicate the relevance of the findings presented in the report to your organisation by circling the appropriate number.

	Very Relevant	Moderately Relevant	Moderately Irrelevant	Very Irrelevant
1. House design	1	2	3	4
2. Social inclusion	1	2	3	4
3. Empowerment	1	2	3	4

5. Which sections of the report do you think may be used to inform future policy and practice within your organisation?

6. Is there anything that you think was omitted from the report or a section that requires further investigation that could be covered in future research?

7. Is your organisation considering or would it consider undertaking research in the area of housing covered by this report?

Name _____

Position _____

Address

Postcode

_____

Tel. _____

Thank you for your time and interest.
Susan Levy

APPENDIX D

MAILINGS:

- LETTER REQUESTING PARTICIPATION IN STUDY
- RESPONSE FORM TO PARTICIPATING IN THE STUDY
- LETTER ACCOMPANYING SUMMARY REPORT SENT TO INTERVIEWEES
- LETTER ACCOMPANYING SUMMARY REPORT SENT TO STAKEHOLDERS

[AGENCY LETTER HEAD]

10th September 1996

Dear

I am writing to inform you about some research that is being carried out by Susan Levy, a geography student at St Andrews University. Susan is interested in talking to you about your house. She is keen to find out how easy it is for you to get around your house, both inside and outside, and if your house has been altered in anyway for you.

This is an opportunity for you to discuss how you feel about where you live, and the results of the study will hopefully help plan for future housing for wheelchair users.

Here at [agency] we can see the benefits of Susan's work and we hope you are able to spend some time talking to her. If you feel you would like to participate in this study, and talk about the good and the bad things associated with your house, please complete the enclosed form and return it to Susan in the stamped addressed envelope provided. Susan will then contact you to arrange a time to meet you.

I hope you are able to participate in Susan's study. Any information that you are able to offer her will be very valuable and will be treated as strictly confidential.

Yours sincerely,

School of Geography and Geosciences
University of St Andrews

Study into:
WHEELCHAIR USERS AND HOUSING IN DUNDEE
by Susan Levy

Having read the enclosed letter, if you would like to participate in the study and agree to me coming to interview you in your house, please complete the following information.

NAME

ADDRESS

POSTCODE

TEL. NO.

Please ✔ the answer that applies to you. Are you aged between 16-64 years? O Yes O No

Please return the completed form in the stamp addressed envelope provided by **October 15th 1996.**

Thank you for your time and co-operation, and I look forward to meeting you in the near future.

Susan Levy

School of Geography and Geosciences
University of St Andrews

Purdie Building, North Haugh,
St Andrews, Fife, KY16 9ST,
Scotland, U.K.

Telephone : 01334 462819
Fax : 01334 463949
e-mail : sll2@st-and.ac.uk

31 March 2000

Dear Alison,

Addressing the housing needs of people with disabilities: social inclusion through empowerment
Susan Levy, University of St Andrews

I hope you are well and remember me coming to visit you a number of years ago to talk about your housing. I apologise for taking so long to get back in touch, however, I have now written up some of the findings of my research in a summary report and have enclosed a copy for you.

The report is being sent to the people I interviewed and service providers (ie Dundee City Council housing department and social work department). I am sending a copy of the report to service providers to inform them of the findings of the research with the ultimate goal of them being able to use the study to improve the service they provide to you and other wheelchair users in the future.

If you feel you want to comment on the report, for example, about something I've written that you disagree with, something that you feel strongly about, or something that was omitted from the report, please feel free to write to me at the address above.

To protect your identity all the names referred to in the report are pseudonyms, except for Susan that refers to me.

Thank you again for your time and interest in this study, without your help the research would not have been possible.

Best wishes for the future

Susan Levy
Research Student

School of Geography and Geosciences
University of St Andrews

Purdie Building, North Haugh,
St Andrews, Fife, KY16 9ST,
Scotland, U.K.

Telephone : 01334 462819
Fax : 01334 463949
e-mail : sll2@st-and.ac.uk

31 March 2000

Dear [agency]

Addressing the housing needs of people with disabilities: social inclusion through empowerment
Susan Levy, University of St Andrews

Enclosed are copies of a report summarising some of the findings of my PhD research on the experiences of wheelchair users living in different types, tenures and locations of housing in Dundee. The report is being sent to you as a means of communicating the results of my study and raising awareness of some of the barriers to social inclusion and empowerment that people with disabilities are facing with regard to their housing. Please distribute the enclosed reports to interested individuals within your organisation.

As part of the on-going research process I am interested in your thoughts on the report and the ways that [agency] is addressing issues of social inclusion, empowerment and house design in relation to people with disabilities. I have included a mini-questionnaire and would appreciate you spending a few minutes responding to the questions. Any additional comments you may have on the questions or report more generally will be most valuable. Please include your name and address on the questionnaire as I may wish to discuss your comments directly with you. Please return the questionnaire to me by **Friday 21 April 2000**, in the enclosed pre-paid envelope.

In addition I would appreciate you forwarding any recently published literature (for example, Housing Plans) that would be relevant to my research.

I hope the report is of interest to you and I look forward to hearing from you.

Yours faithfully

Susan Levy
Research Student

APPENDIX E

SUMMARY REPORT

Addressing the Housing Needs of People with Disabilities:
social inclusion through empowerment

Susan L. Levy

March 2000

School of Geography & Geosciences, University of St Andrews
St Andrews, Fife, KY16 9ST

1. MAIN FINDINGS

House Design

- *There is scope for incorporating smart technology into wheelchair users' homes.*
- *There is a need for more two-bedroom dwellings for couples and single wheelchair users.*

Social Inclusion

- *Social inclusion has a locational specificity to it: with some locations offering greater opportunities for social inclusion and independent living than others.*
- *Owner-occupiers are better able to diminish their experience of social exclusion through voluntary intra-urban migration and/or adapting their house.*
- *An imbalance in the mixing of people of different ages, and the inaccessibility of communal facilities and unadapted housing, are inhibiting social interaction in sheltered housing.*
- *93% of interviewees living in sheltered housing would like to move house, yet 57% value the security and independence transferred to them by the support services of a warden on call.*
- *Sheltered housing is perceived, by people living in non-sheltered housing, as stigmatising, providing for the needy and weak in society, and reproducing negative imagery of disabled people.*
- *The small scale clustering of three or four (non-warden linked) wheelchair houses integrated into mainstream housing successfully fosters social interaction.*

Empowerment

- *Social housing tenants feel they have little choice, control or power over decisions governing their housing.*
- *72% of housing association tenants and 67% of local authority tenants find it 'difficult' or 'very difficult' to find housing information.*
- *75% of interviewees found service providers helpful.*

2. INTRODUCTION

2.1 BACKGROUND TO STUDY

As housing is increasingly recognised as playing a pivotal role in the social exclusion of certain groups within society, the concept of housing being narrowly defined by bricks and mortar is becoming a relic of the 20th Century. The quotation below, taken from Scottish Homes revised Care in the Community Policy, captures the essence of housing practitioners' changing role at the start of the 21st Century:

> *to enable people with particular needs to lead lives as close as possible to those of other tenants and owner occupiers, with a similar degree of choice, flexibility and control in their housing environment.*
>
> Scottish Homes, 1998

The expanding role of service providers (both housing and support) is that of enabling the social inclusion of marginalised groups into their respective communities, and facilitating the empowerment of clients to be involved in decisions influencing their housing. The role of housing practitioners is therefore becoming more holistic, aimed at ameliorating the housing experience of people, including those with disabilities, across all tenancies.

Housing experience is used in this study to refer to:

- the bricks and mortar of good design;
- the possibilities for social inclusion in a given location; and
- the choice, control and involvement that an individual has over decisions governing his/her home.

This report addresses these three aspects of housing in Dundee with reference to the housing experiences of people with disabilities, and in so doing highlights the disparity between social housing tenants and owner-occupiers. It is a guiding principle of Scottish Homes work and an objective of the Scottish Executive to eradicate such disparities between tenancies.

The implementation in 1993 of the NHS and Community Care Act 1990 facilitated the transformation of the living environments of people with disabilities. The essence of the 1990 Act was to enable people with community care needs to live in as homely environment as possible. Dundee City Council has, through progressively expanding its special needs housing stock, the best provision of special needs housing in Scotland (Public Health Alliance, 1993). Despite this excellent record Dundee's wheelchair users are experiencing social exclusion in their home environment, a process of exclusion which is exacerbated by an insufficient supply of adapted and purpose built dwellings.

The 1990 Act also laid down the requirement of service providers to consult with and listen to service users, yet there is little evidence to suggest that service providers are

fulfilling their commitment to the Act in this respect. In addition, a number of studies have highlighted the inaccessibility of relevant housing information for people with disabilities (see Eccles, 1995; Disability Scotland, 1994), a problem which Lothian Council have attempted to resolve by creating a Disabled Person's Housing Service.

Throughout Scotland while there are isolated examples of good practice by housing practitioners, such as that by Dundee City Council and Lothian Council, there are also numerous studies demonstrating the shortcomings in housing practice and community care (see Lund & Foord, 1997; Hudson et al., 1996; MacFarlane & Laurie, 1996). As policy interest grows in the social inclusion and empowerment of marginalised groups, there is growing evidence of a need to re-evaluate the policy and practice of community care.

Scottish Homes have spearheaded the policies that address the interface between housing and social inclusion. As the national housing agency for Scotland, Scottish Homes commitment to guiding and overseeing the implementation of housing practice that is sensitive to the concept of social inclusion is crucial. Through positively valuing people with disabilities and recognising that certain types of housing are disabling, Scottish Homes aims to guide housing providers in actively working towards the incorporation of people with disabilities into their respective communities. In partnership with local authorities, housing associations, the voluntary sector, private developers, and local communities, Scottish Homes new housing policies are working to diminish a legacy of ableist policies and practices that have segregated, excluded and marginalised people with disabilities.

The philosophy that has influenced this new holistic approach to housing is grounded in the social model of disability. The social model focuses attention on physical, social and attitudinal barriers that inhibit and prevent people with disabilities from participating fully in society. Responsibility for tackling disabling barriers thus becomes society's responsibility, rather than the onus being placed on the disabled individual to adapt to an inaccessible environment. As Zoe (an interviewee in this study) reflecting on her experience of living in a disabling society, perceptively remarks,

> *The world is designed by thirties males, average height, white, walkie-talkies and if you don't fit the mould, well tough.* Zoe, interviewed 8/12/96

As housing providers become increasingly sensitised to the social model of disability and adapt their housing practice, there will be a greater need than ever before to consult with and listen to the housing experiences of service users. This acquired knowledge can then be used as a means of informing future policy decisions and housing practices. This study addresses the need to consult with and listen to users, being primarily qualitative in nature, it was designed to enable people with disabilities to talk freely and openly about their experiences, expectations and perceptions of their housing.

The findings presented in this report are targeted at policy makers, housing and other service providers, as a medium for communicating the knowledge and understanding people with disabilities have of their housing needs. Only through the collaboration

of housing practitioners and service users, by way of shared decision making over housing needs, will optimal housing solutions be achieved in the future.

2.2 STUDY OBJECTIVES

This study investigated the interface between house design, social inclusion and empowerment across different tenures and locations of wheelchair users' housing in Dundee. The objectives of this qualitative study were threefold:

- To enable interviewees to talk openly and freely about their experiences, needs and perceptions of the housing presently available for wheelchair users in Dundee.
- To investigate the role of tenure and location in interviewees experience of house design, social inclusion and empowerment.
- To communicate interviewees' experiences and housing needs to policy makers, housing practitioners and other key service personnel.

2.3 METHODOLOGY

Data was drawn from in-depth, semi-structured interviews conducted with 50 wheelchair users, living in Dundee, between December 1996 – May 1997. The 50 interviewees are a small sample of Scotland's total wheelchair population, but the study was not designed to be necessarily representative of wheelchair users generally. Rather, the data generated from the interviews represents a rich and detailed insight into a heterogeneous group of wheelchair users' experiences and perceptions on house designs and adaptations, social exclusion and empowerment in a Scottish urban environment at the end of the 20th century.

Contact was made with the interviewees through the Dundee Limb Fitting Centre (44% of interviewees), Dundee City Council (DCC) housing department (30%), DCC social work department (SWD) (16%), Margaret Blackwood Housing Association (MBHA) (6%), and Dundee ACCESS Group (4%). The use of multiple agencies for identifying potential interviewees, was the key to accessing a group of wheelchair users living in different types, tenures and locations of housing across Dundee.

2.3.1 House Type and Tenancy of Interviewees

The largest group of interviewees in the study were living in mainstream adapted housing (36%), followed by those living in sheltered housing (30%), purpose built wheelchair housing (22%) and mainstream unadapted housing (12%). Interviewees living in local authority housing constituted the largest tenancy group (42%), followed by owner-occupiers, including shared owners (34%), Housing Association tenants (20%) and a private tenant (2%) and tied tenant (2%) (Table 2.1).

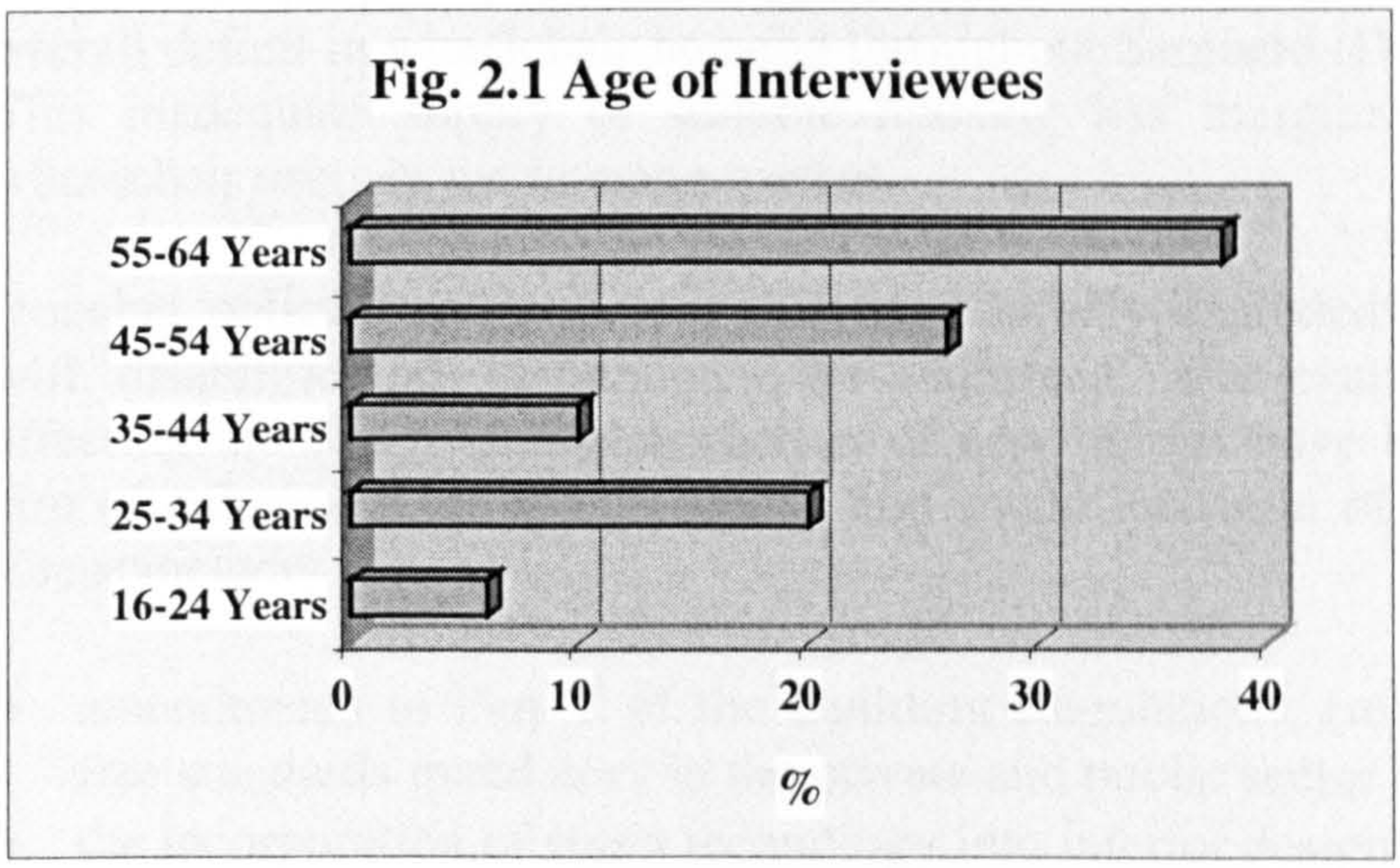
Table 2.1 House type by tenancy

	A	B	C	D	Total
DCC Tenant	46%	17%	67%	60%	42%
HA Tenant	36%			40%	20%
Owner-occupier	18%	72%	33%		34%
Others*		11%			4%
Total	100%	100%	100%	100%	100%

A Mainstream Unadapted Housing
B Mainstream Adapted Housing
C Purpose Built Housing
D Sheltered Housing
* Private tenant and tied tenant

2.3.2 Demographics of Interviewees

Fifty eight percent of interviewees were female and 42% male, however gender was not found to be a significant variable in the analysis of the data, and is therefore not discussed in the findings of the report. All interviewees were white, no non-white wheelchair users responded to requests to participate in the study. The age of interviewees was restricted to adult wheelchair users between 16-64 years, the largest age group being the 55-64 age group (38%) (Fig. 2.1).



2.3.3 Data Collection and Analysis

The in-depth interviews were semi-structured around a questionnaire, a format designed to allow interviewees to expand and talk at length on a subject. Interviews varied in length from 45 minutes to 2 hours and 30 minutes. The interviews took place in the interviewee's home and, with their permission, were tape-recorded. The majority of interviewees were keen to talk and appreciated having the opportunity to 'open up' to someone they perceived as an interested, neutral outsider:

> *... it's just good to know that there are people who want to help you know, or they want to try to make an impact. I know it's not easy and one person can't do it all, but it's nice to know there are people out there who are prepared to come in and ask questions like that, coz it's the little things that are important at the end of the day. Like if all the little things were taken care of, I'd have more energy to face the bigger things, so you could do what you really want to do instead of struggling to do the little things.* Liz, interviewed13/3/97

All the names used in this report are pseudonyms to protect individuals' identity, other than Susan, which refers to the interviewer and author of the report.

3. HOUSE DESIGN

Dundee City Council has over the last couple of decades progressively expanded its supply of special needs housing (City of Dundee District Council, 1993). The Public Health Alliance in Scotland found, of all the Scottish local authorities, Dundee had the best provision of special needs housing for people with disabilities (Public Health Alliance, Scotland, 1993). Despite this excellent record there are still insufficient adapted and purpose built dwellings for Dundee's wheelchair users, a reflection of an overall deficit in wheelchair housing throughout Scotland (Disability Scotland, 1994). This inadequate supply of suitable housing has marginalised and disadvantaged wheelchair users in the housing market.

Housing policies and practices that have largely excluded and undervalued people with disabilities are beginning to be addressed. For example, significant changes affecting the design and construction of new houses have been introduced with the aim of enhancing the independence and social inclusion of people with disabilities. These include:

- amendments to Part T of the Building Regulations, (making building to barrier free standards mandatory in the private and public sector from 17 April 2000); and
- the incorporation of smart technology into interior design features.

Building to mandatory barrier free standards, wherever possible and feasible, will over time make a significant percentage of the total Scottish housing stock 'visitable' for wheelchair users. Social and architectural barriers, which presently lead to the social exclusion of wheelchair users, will thus begin to be erased. In addition, the standardisation of level or ramped entrances to houses will eliminate the external architectural differences between special needs and mainstream housing. However, there is still great demand and scope for improving the design and expanding Scotland's wheelchair housing stock. It is the objective of this section of the report to examine the interior design of wheelchair users housing in Dundee in the late 1990s and identify architectural barriers within the homes of interviewees.

This study found that wheelchair users benefit from the greater independence and freedom of movement provided by suitably designed homes. Increased independence, a less stressful life, and greater energy levels are some of the benefits interviewees were experiencing when the barriers, which had made day to day life a struggle in an unsuitable house, were eliminated. As Gail says,

> *The extension and the facilities actually put my life back into perspective, more in control, you know. I could do what I wanted when I wanted without any help, without waiting till somebody else was available.* Gail, 30/1/97

However, the research establishes that certain housing features need to be re-evaluated, specifically:

- there is scope for incorporating innovative smart technology into the design of windows, doors and kitchens; and

- there is a demand to make more two bedroom houses available for couples and single wheelchair users.

3.1 TENANCY

Since the 1980s housing associations have become the principle providers of new social housing, including special needs housing (Langstaff, 1992). It is therefore not surprising to find that housing association tenants are living in housing that is better designed for wheelchair users' needs than local authority and owner-occupied housing (Table 3.1).

All interviewees in housing association dwellings had a ground floor bathroom, an adapted toilet, ground floor bedroom, raised electrical sockets, wide door frames, accessible door handles, accessible light switches, central heating, a parking space and dropped kerb by their house.

Table 3.1 Design features and adaptations by tenancy

	A	B	C
General			
Level access/ramp to front door	86%	100%	42%
Wide door frames	71%	100%	33%
Raised electrical sockets	81%	100%	42%
Accessible door handles	62%	100%	17%
Accessible light switches	76%	100%	25%
Community alarm/warden	71%	71%	42%
Open all windows	5%	14%	17%
See out of majority of windows*	48%	29%	58%
Double glazing	52%	29%	92%
Central heating	91%	100%	100%
Bathroom			
Ground floor	91%	100%	75%
Level shower	67%	71%	67%
Adapted toilet	52%	100%	33%
Grab rails by toilet	43%	86%	50%
Kitchen			
Lowered work surfaces	62%	86%	33%
Adapted taps	62%	86%	17%
Accessible oven	62%	71%	33%
Bedroom			
Ground floor	91%	100%	58%
Outside			
Parking space beside house	19%	100%	67%
Accessible driveway	14%	86%	58%
Dropped kerb by house	38%	100%	67%

A DDC Tenants
B HA Tenants
C Owner Occupiers

* bathroom windows were excluded

3.2 ARCHITECTURAL BARRIERS

Recurring problems were found across all tenancies with the opening and closing of windows. Additional problems with windows were identified primarily in social housing (both local authority and housing association properties), namely: the absence of double-glazing and badly located windows that prevented interviewees from being able to see outside. These problems were found to be disproportionately high in housing association dwellings despite the overall high standard of facilities in such properties (Table 3.1).

Windows were found to have an important social function for interviewees, enabling them to see and communicate with friends and neighbours. This study confirms Rowles'1981 findings that a suitably designed window enables people to feel a part of their local community, when they are unable to physically participate in that community. Both the height and location of windows were therefore found to be of importance in the design stage of wheelchair housing, to ensure wheelchair users could, whenever possible, have a view onto a communal or public area. As Marina, Donald and Megan point out,

> *Folks go up and down with the bairns and the pram, coz it's the sea just there. That's the only contact I've got with sitting here, coz I canna go out myself.*
> Marina, 20/2/97

> *It would have been nice to see people. But you see I canna get up the steps and everything, and there's a wee walled garden, which I look at from the living room window, a drying green, a gable end of a house and a load of birds. I would have liked a house on the front of the block (with a view of the road and people passing). I never thought of the front, the front houses weren't nothin' at the time, it's just once you're in the house, you know and you're looking at the terrible view.* Jim, 19/2/97

> *You know it's just a small detail and like, but it is very annoying not being able to see out of your windows, especially at the front. What I'm saying if they were doing other houses like this wouldn't it be nice if you could see out the windows?* Megan, 28/1/97

The weight and stiffness of internal doors also created problems for interviewees. For example, when Liz moved to a new purpose built house she discovered to her disappointment, that despite all the architectural features that enhanced her independence, the doors in her house restricted her independence.

> *These doors are an absolute nightmare, like me trying to open these doors at the moment, they're heavy, and awkward, and I'm having a particularly good spell at the moment. So I don't like them no.* Liz, 13/3/97

Of all the rooms in the house, kitchens were found to be associated with the most problems.

> *Susan: Has the kitchen work surface been lowered?*
> *Iris: Well the problem is the fact that Alan (husband) is very tall, and I'm in my wheelchair, and they adapted it, but it isn't really suitable for either of us. It's too low for Alan and it's really too high for me getting in at the sink. And the cupboards are all too high.* Iris, 28/1/97

> *They were trying to give us a fully adapted wheelchair house, which isn't what we wanted, because I can't do the things in the kitchen, so we just want a partially adapted house. 'Oh well you've really got to get fully adapted'.*
> Morag, 21/1/97

Iris and Morag speak for many interviewees who were having problems balancing their needs as wheelchair users with the needs of other people in their household. Both Iris and Morag are in social housing and epitomise the limited choice available to this tenancy group (see Section 5.2.1). In contrast owner-occupiers were found to have kitchens that best suited their family needs, rather than the assumed (standardised) needs of a wheelchair user.

Owner-occupiers like John were either not lowering the height of a standard work surface or raising the height of work surfaces that had been designed for a wheelchair user. John and his wife, for example, decided to have the work surface lowered in their kitchen so that it would be more convenient for John's wife to do the cooking. Other interviewees concur with John, that it was dangerous for them to cook, they knew they were unable to hold heavy, hot pans, and generally it was felt that it was not essential to have lowered work surfaces that could inconvenience the people who would be doing the cooking. Hence, the kitchen was a room that was infrequently used by many interviewees, even when it was adapted. As Gail joked,

> *I've gone into the kitchen, instructed Bruce right do this and not to do that. I'm not very good at working, but oh boy am I good gaffer.* Gail, 6/2/97

Additional problems that were found to be associated with kitchens were:

- restricted leg room under sinks and work surfaces, and
- inaccessibility of cupboards, both wall and ground level units.

3.3 SMART HOMES

Technology has been incorporated into many aspects of our everyday lives, for example, automatic doors into shops, and central locking and electric windows in cars. Yet as Gann et al. (1999) note much of the way we live our lives at home has remained unchanged; advances in home infrastructure have not matched the advances in technological products. The concept of smart homes is redressing this imbalance through harnessing some of the technologies that are useful in other settings to improve the quality, independence and security experienced by disabled and older people in their own homes.

Technology was introduced into special needs housing with community alarms in 1977 (Macnaughtan, 1997). The community alarm was perceived by interviewees to be an asset for enabling them to live independently. Although interviewees rarely, if ever, used the service, they saw it as invaluable.

> *Kevin: ...that's (community alarm) another insurance policy almost.*
> *Susan: Have you ever used it?*
> *Kevin: No but it's always good just to have for insurance.*
>
> Kevin, 2/4/97

The notion of smart homes is extending the parameters of how technology can assist people with disabilities to live independently in their own homes (see Scottish Homes, 1999, Fisk, 1999). The Edinvar Housing Association has pioneered the possibilities

of smart technology in a demonstration flat in their St Leonard's project in Edinburgh. The smart home can close and lock windows and doors, adjust the height of kitchen units and sinks, turn lights on, close curtains, flush the toilet, shut off the gas, send an automatic emergency call, monitor movement, and broadcast reminders, for example to take medication (Scottish Homes, 1999). The problems identified in this study with the opening/closing of windows and doors, and access in the kitchen are just three features that interviewees had problems with in their home, all of which are now able to assimilate smart technology, enabling wheelchair users to live more independently.

3.2 HOUSE SIZE

An inadequate supply of suitable housing was found to be exacerbated by the size of the houses in the available housing stock. The research suggests that there is limited demand for one-bedroom houses but a greater demand for two bedroom houses for single people and couples. Single interviewees felt an additional bedroom would enable their carer to stay overnight whenever the need arose. Whereas couples felt an additional bedroom provided them with the flexibility of sleeping separately whenever the interviewee was experiencing pain or discomfort that was likely to prevent them and consequently their partner from sleeping.

Although not raised by any of the interviewees, it was apparent that dining facilities were absent in over 50% of houses. In the absence of space for a dining/kitchen table interviewees were eating off trays perched on their knees. Well-designed kitchens in MBHA dwellings incorporated a useful low-level breakfast bar/table that divided the kitchen and living room. This feature had a dual function of providing an accessible work surface and space for people to sit together to eat. Unfortunately, the design of similar features in other housing association properties was less successful, as Alex found out.

> *The breakfast bar, when I saw it I thought that's at the height for a normal breakfast bar, it is too high. Right they said they were going to put in a breakfast bar low enough for me to eat off. Sorry but I don't want to stick my face in the plate, but that is what I'd have to do. It's just too high, but then they just don't think about disabled people.* Alex, 11/4/97

In demonstrating the significance of seemingly insignificant features in the home - the social value of windows, having somewhere to eat with friends and family - the social importance of a home is highlighted in addition to the 'bricks and mortar' of good architectural design. Growing interest in social housing needs and social inclusion by politicians (Scottish Office, 1999), academics (Marsh & Mullins, 1998) and housing practitioners (Scottish Homes, 1998, 1997) is impacting on housing practice by heightening awareness and sensitivity to the holistic housing needs of clients.

4. SOCIAL INCLUSION

Social inclusion has achieved prominence in social policy since the late 1990s as politicians attempt to ameliorate the lives of people who have been marginalised, disadvantaged and excluded from mainstream society. This includes people with disabilities as well as more readily identifiable groups such as the homeless and unemployed. Recent interest in social inclusion has raised the profile of social barriers alongside economic barriers to inclusion. Economic barriers, such as poverty and unemployment, remain important but are now recognised as being interwoven with social barriers, relating for example, to particular groups based on gender, disability, ethnicity or sexuality and/or poor health and inadequate housing (Scottish Office, 1999). Scottish Homes have assimilated the salience of the connection between housing and social inclusion through prioritising social inclusion as a community care objective. 'By inclusion we mean integrating those who find themselves socially and economically excluded. ... In a Community Care context, this means assisting those with particular housing needs, both those currently living in unsuitable housing in the community and those who have been socially excluded through living in institutional establishments' (Scottish Homes, 1998, p.18).

The findings from this study indicate that social inclusion, in relation to housing, has a locational specificity to it: with some locations offering greater opportunities for social inclusion and independent living than others. Moving house and sheltered housing were found to be closely related to interviewees' experience of social inclusion and exclusion, specifically:

- moving house can have the affect of eroding or amplifying physical, social and attitudinal barriers to inclusion.
- An imbalance in the mixing of people of different ages, and inaccessible communal facilities and unadapted housing are inhibiting social interaction in sheltered housing.

These two barriers to inclusion are addressed below and in so doing housing tenure is identified as playing a key role in the inclusion or exclusion of disabled people.

4.1 MOVING HOUSE

For the majority of people moving house is an inevitable occurrence in their lives. Even so it requires a lot of planning, and often results in individuals being uprooted from a familiar social and physical environment. For people with disabilities these factors are exacerbated by an inadequate supply of accessible and affordable housing which restricts their choice in the housing market.

4.1.1 Tenancy

The gravity of an inadequate supply of accessible and affordable housing is manifest in the frequent and involuntary moves social tenants have to make before acquiring a suitable house. As Gillian testifies, after her fifth move, she has eventually found a house that meets her family's needs.

> *This house has made a big difference, all the moving you have to do isn't good. You wait so long for a ground floor, so I went from a first floor to third floor, to ground floor to here.* Gillian, 12/2/97

For people with disabilities, as for most people, moving house entails exchanging security and familiarity with the unknown and unfamiliar. In addition to establishing a new social network, people with disabilities must also learn to read and predict the physical layout of their new neighbourhood: the location of dropped kerbs, steps and accessible amenities, all of which requires time and energy. It is therefore not surprising that people with disabilities often resist moving. (The exception being where an individual is experiencing social exclusion in their present neighbourhood which is pushing them to seek change, see below).

The findings of this study highlight the necessity to consider the holistic housing needs of individuals, that is their physical, social and medical needs ought to be considered in parallel, if the health, well being and social inclusion of each individual is to be prioritised. For people like Ben a move to a social housing scheme on the periphery of Dundee is perceived as creating rather than dismantling barriers to social inclusion.

> *I could think it would make people quite anxious, anybody in a wheelchair. 'Oh just listen we're going to take you out of a nice friendly warm environment, by all your friends and where you know where everything is and shove you in the middle of a scheme where you know nobody, you've never been in this end of the town, you haven't got a clue where you are, that's where we'll put you.' A normal person wouldn't like it, but never mind somebody who already has enough to cope with, without having that kind of mental pressure as well.* Ben, 9/1/97

Ben is a local authority tenant and, while suitable social housing for wheelchair users remains a finite resource, he feels he has little choice or control over his housing, in relation to both house type and location. Morag, like Ben, is a social housing tenant and epitomises the dilemma faced by tenants in social housing: of deciding whether to remain in unsuitable accommodation or to move to a new and unknown neighbourhood. She would like to adapt the house, which she and her husband have invested time and money in, creating a place with fond memories, in a supportive and familiar community. However, Dundee Council has told her that there are insufficient resources 'to go around adapting every house' and that she must move house. Morag feels disempowered and silenced by a system that appears unable to meet her housing needs.

> *I like my house, I dunna really want to move out. I mean every bush in that garden, we bought, we went to nurseries, there was nothing in that garden, not a thing, and it was up to the window with long grass, it was just a wilderness, and Jim done all that, cut out circles. Every bush and flower tells a story, that bush by the fence was got on one of our anniversaries.* Morag, 21/1/97

The limited choice and control over housing decisions available to social tenants contrasts with the experience of owner-occupiers, where the scenario is very different.

Owner-occupiers are eligible under the Chronically Sick and Disabled Persons Act, 1970, to apply to their local authority for a Home Improvement Grant to assist with the cost of adapting their property, enabling owner-occupiers to 'stay put' if that is their choice. Anna, for example, did not want to move house. Her family home, owned by her mother, was a base for social interaction, security, warmth and childhood memories. Anna successfully applied for a grant from Dundee Council, thus enabling her to remain in the family home.

> *As I say to the social worker, Anna's happy in this house, if she wants to go to a 'disabled house' she can go. But she made it quite clear to me, that no way am I going out of here, unless it's really, really necessary, but if you can do things in this house for me, I want to stay. So when they decided that they could do it this way, she says well 'I'm quite happy'. So I said her happiness is important, if she's happy in this house, she might be put in a 'disabled house' with even more things in it, but what's the point if she's not happy? I says that's not any use, she's got everything around her, but she's not happy in it. I says that could tell on her health, she's happy here and she knows the people about here. That's the main thing.* Betty, Anna's mother , 31/1/97

The findings from this study confirm Anna's and her mother's fears that the benefits accrued from living in a purpose built house may be offset by the social environment of the house. Housing association tenants were found to be less likely to feel integrated into their local communities, despite living in houses that were architecturally superior for wheelchair users than local authority and owner occupied houses (Table 3.1).

When an individual is experiencing social exclusion a move will be welcomed. As Kevin found, a move can be invigorating when physical, social and attitudinal disabling barriers are eliminated from an individual's local environment. Kevin highlighted the importance of having friends and shops close by in an accessible environment, and how these are highly valued and sought after criteria alongside a well-designed house.

Being centrally located was found to have the additional advantage, for owner-occupiers and social housing tenants, of eliminating the need for transport into town. Questions about transport were particularly pertinent for interviewees without a family car (48% of interviewees did not have a car in their household). However, the topography of Dundee, especially the very steep slope from the city centre up to the Hilltown, can diminish the benefits of being close to the city centre, as Ben, who lives in the Hilltown, knows all too well.

> *It's like why did they build sheltered housing on a hill? This is where we're going to put our grandmothers who have trouble walking and people in wheelchairs, right where will we put them? There's a good site, on the Hilltown, we'll put them there at the top. Who's idea was that? Even if you could get down, how the hell are you going to get back up? 'Cab', 'Yeah where you going pal?' 'Top of the road'. Two hundred yards up the top of the road. I feel stupid getting a cab. I get a cab from here to the shop, 200 yards down the road, because if it wasn't on an incline I'd manage. So that was a mistake building sheltered housing at the top of the Hilltown.* Ben, 9/1/97

The findings from this study demonstrate that owner-occupiers, like Kevin, have greater freedom and power, compared to social housing tenants, to exercise choice in the housing market. Owner-occupiers are better able to diminish their experience of social exclusion through voluntary intra-urban migration or adapting their house.

4.1.2 Accessing Information to Make an Informed Move

Part of the success of moves by owner-occupiers arises from the move being well planned. Owner-occupiers it was found find it easier than social housing tenants to access relevant information in relation to their housing (Fig. 5.1), and are more likely to find information for themselves rather than wait to be informed by service providers. It follows that service providers could help reduce the number of unsuccessful moves made by their clients if they provided their clients with more information about the neighbourhood in which their client had been offered a house. Social housing tenants are offered the choice of three houses before being relegated from the top of the housing waiting list. Service providers could, for example, assist their clients in making a decision on whether or not to accept a house by:

- broadening the information that service providers offer prospective tenants to include demographic information about the neighbourhood, in addition to information about the location of shops, doctor surgeries and other amenities; and by
- allowing more time for house visits and offering the choice of additional visits if their clients feel they need to return to view the house.

If this information was available moves that exacerbate social exclusion could well be reduced. Helen, for instance, is unlikely to have moved to her present house had she had access to more information about the neighbourhood. When I met Helen she was extremely disappointed and depressed by her recent move to sheltered housing. She felt isolated and lonely, surrounded by older people and she felt let down and annoyed by the failure of service providers to inform her about the reality of living in sheltered housing.

> *Helen: There is one thing I really disagree with, that's social workers, or OTs and the wardens. When I first came here ... I admit I thought it was the right move, and from April to November no-one said anything. I thought OTs and social welfare are bound to have the information and I'm quite sure if they thought a bit more laterally they could think about how they would feel if they were in my situation. But I get the feeling that you're just a name to them and when they get you allocated that's their job over and done with. ...*
> *Susan: Did you come and see the house before you moved in?*
> *Helen: Oh they showed me it, but the day I came with mum and dad, the girl from the housing came and twenty minutes later a taxi came and she was more concerned about getting away to her office than explaining to me about the house and I felt a bit hurried. She kept saying, 'Come on, come on my taxi is here'. And now looking back, dad wished he had offered to take her back to her office, because he realises that I hadn't had long enough to really think about the house. ... Everyone's got different needs and they don't take them into account and they don't even try to put themselves in the situation.*
>
> Helen, 6/2/97

4.1.3 Moving House or Staying Put

Paradoxically, despite the uncertainty associated with a move by social housing tenants, the majority interviewed for this study, would, if offered a choice, have preferred to move house (86% local authority tenants) rather than adapt their present house (9% local authority tenants). In contrast, owner-occupiers were more settled, preferring to stay put and adapt their house (75%) (Fig. 4.1). The desire of owner-occupiers to stay put appears to stem from a stronger sense of attachment to a house and belonging to a neighbourhood. Sixty seven percent of owner-occupiers felt that they lived in a supportive neighbourhood, compared to 43% of local authority tenants and 29% of housing association tenants. These subjective feelings are important criteria for judging an individual's sense of inclusion in a community. However, it should be noted that whilst owner-occupiers were more likely to feel they could call on their neighbours for help and support, very few interviewees, across all tenancies, were involved in community activities. There was little evidence of 'strong communities' the government is keen to promote. 'Strong communities are vital to an inclusive society. Strong communities provide the bulwark against the development of social exclusion in individuals and families' (Scottish Office, 1999).

Fig. 4.1 Interviewees preference to adapt or move house by tenancy

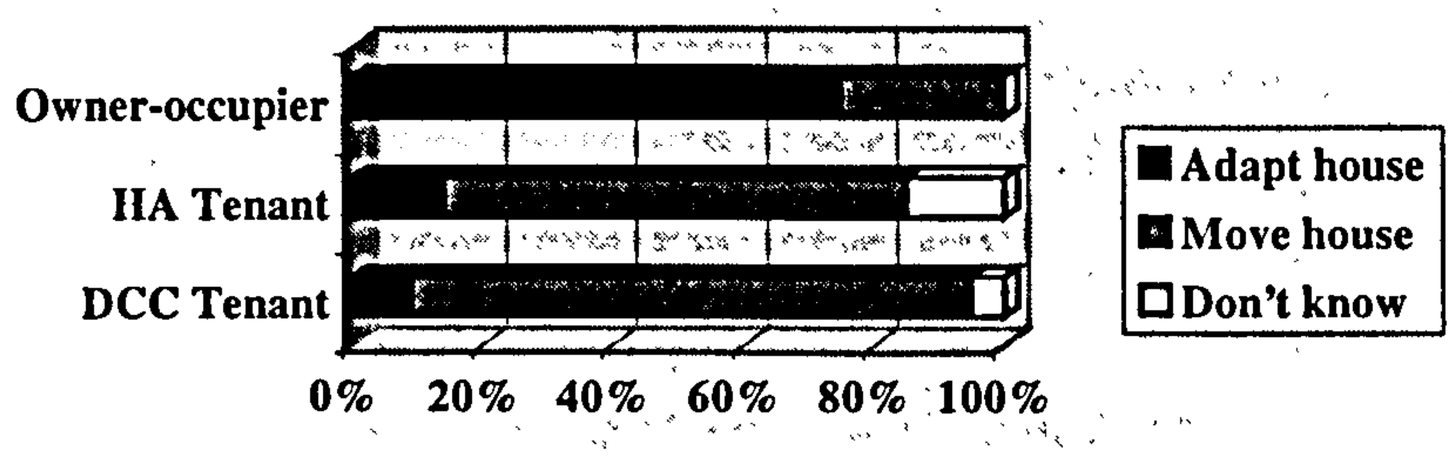


Fig. 4.2 Interviewees preference to adapt or move house by house type

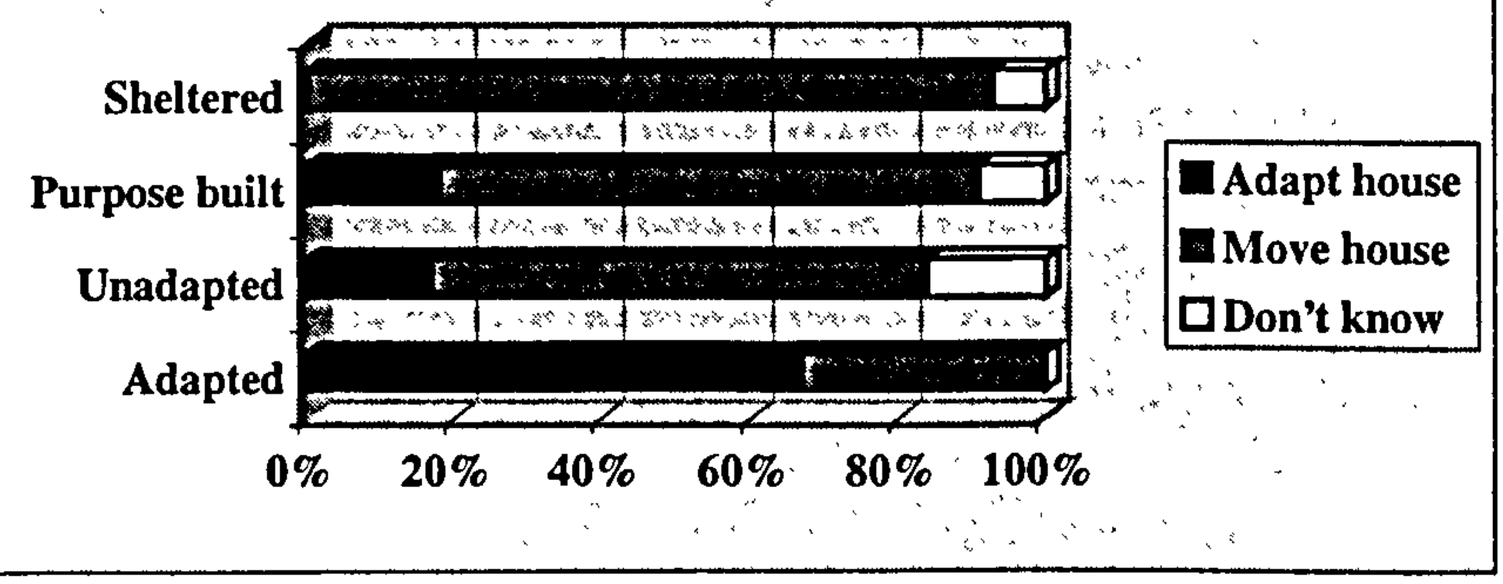


Fig. 4.1 and Fig. 4.2 summarise interviewees' preference for adapting their house or moving house, and reveal how social housing tenants are more inclined to want to move house than owner-occupiers. When house type is considered in relation to these variables, interviewees in sheltered housing were disproportionately more likely to

want to move house (93%) than interviewees living in other types of housing (Fig. 4.2). The study found the unique nature of sheltered housing, both its social composition and its geographical segregation from mainstream housing, is not always conducive to fostering social inclusion.

4.2 SHELTERED HOUSING

Sheltered housing is perceived as an attractive form of accommodation for some older people and/or people with disabilities, the main advantages being, 'the ready availability of support combined with individual facilities and the prospect of social contacts' (Hudson et al. 1996, p.20). Alice, for example, is attracted by the idea of sheltered housing and the expected social benefits of communal social activities and a warden on call. She is optimistic that if she were offered a house in sheltered housing, it would enable her to re-establish a social life, to get out and be a part of her local community.

Sheltered housing schemes are, by their very nature, home for new and heterogeneous populations, rather than established, supportive communities. Sixty per cent of interviewees living in sheltered housing had been living there for less than 5 years, compared to 33% in unadapted housing, 27% in purpose built housing and 22% in adapted housing. The findings in this report indicate that there are certain factors that are inhibiting positive social interaction when people move to sheltered housing schemes, namely:

- an imbalance in the mixing of people of different ages, and
- inaccessible communal facilities and unadapted houses.

4.2.1 Mixing of people of different ages

Dundee Council has invested large amounts of money in sheltered housing and in so doing they have exceeded national guidelines set for sheltered housing (Dundee City Council, 1993). However, this study suggests the need to exercise caution in the allocation of sheltered housing to ensure that the social needs of prospective tenants are considered in parallel with their medical and support needs. Sheltered housing was designed to cater for the over 65s, yet over 50% of the study respondents living in sheltered housing were under the age of 55 (Fig. 4.3).

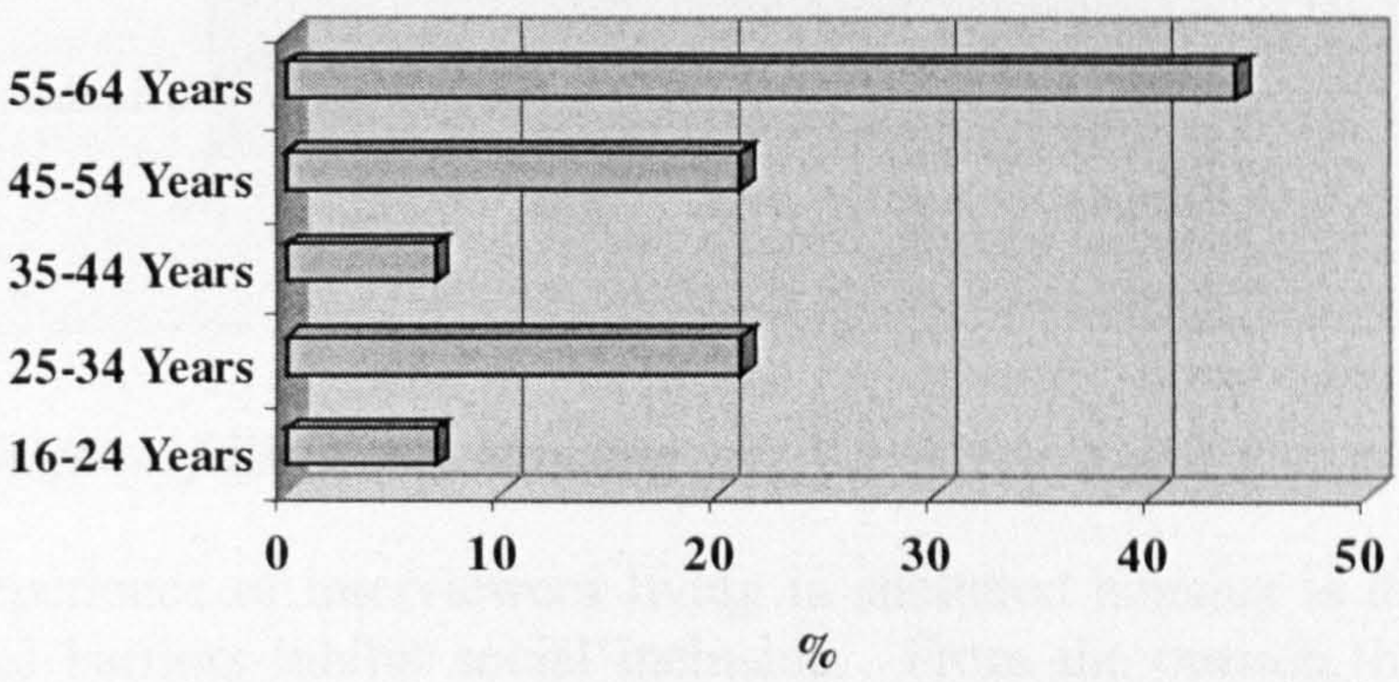
The results of this study demonstrate the social mix of people living in sheltered housing is crucial in facilitating positive social interaction. The mismatch of need created through placing young people in environments of predominantly older people can be a catalyst for social problems and feelings of social exclusion. As Helen (35 years old) and Gillian (37 years old) maintain, the age difference between them and the other tenants has excluded them from developing a local social network.

> *No, no-one told me when I came here that this is a colony of elderly people, which means the grey hair, white hair people. There are only really two people that I can talk to here. So I visit Jill on Monday and I see Elaine now and again. But I sometimes go into the nursing home on the corner and I like it because they're a lot younger there, even though they've got problems, ... it's a bit of a change to meet someone who isn't repeating what they say every*

five minutes. This was a major mistake coming here. … A year at the complex comprises of a fund raising bingo, a Christmas party, a concert which is old folks singing and I'm not very enthusiastic about. Helen, 6/2/97

They have a communal lounge right, they built it with these houses right, but for pensioners right. All the houses round here are pensioners, other than me and the girl next door, everyone else is over 65. So I mean there's no kids, so it's bad for the kids. So this lounge what they did right, they had a tenants meeting when we moved in, the pensioners said, we don't want kids, so my kids can't get in. Gillian, 12/2/97

Fig. 4.3 Age of interviewees living in sheltered housing



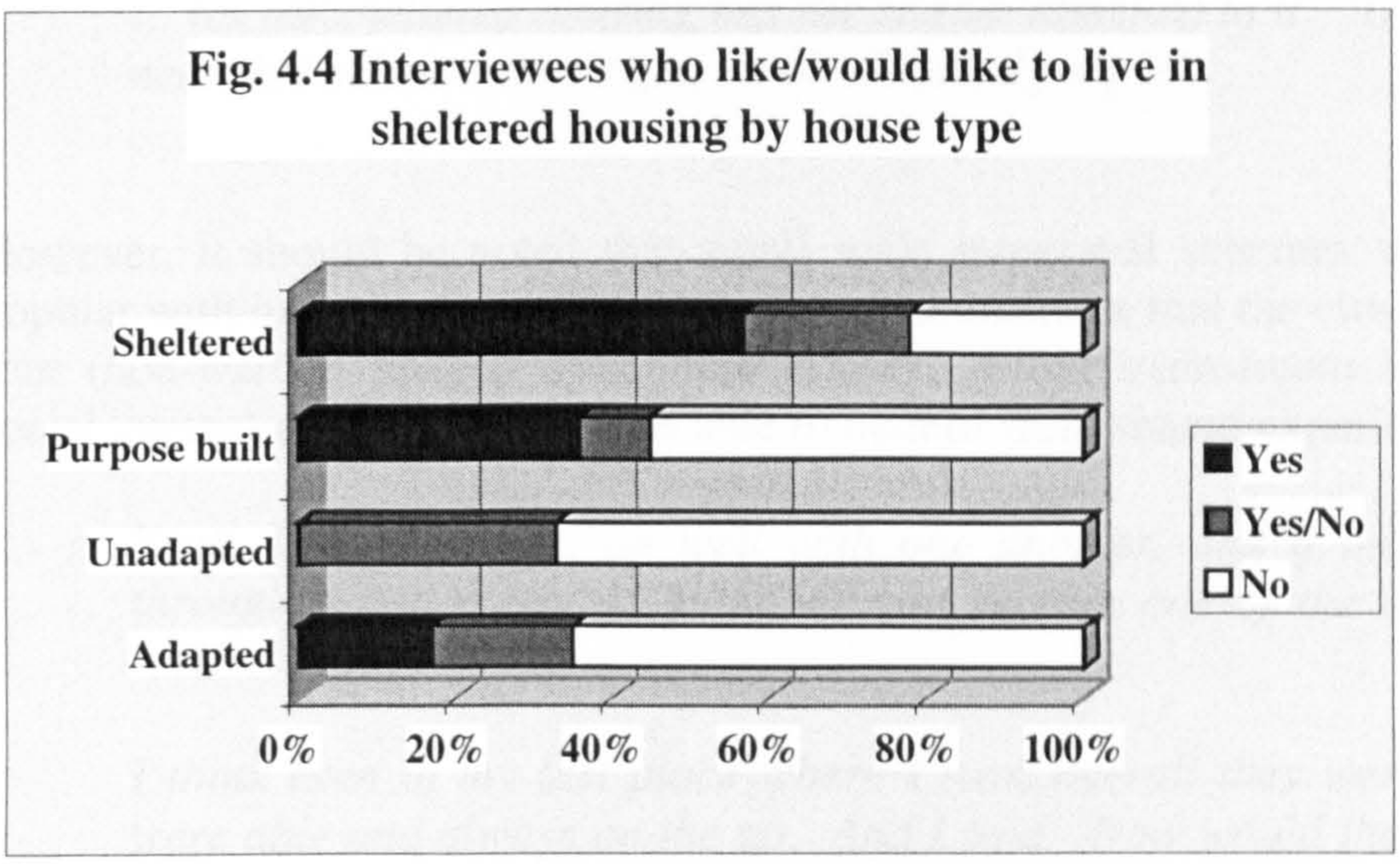
For Jim, physical barriers, in the form of steps up to other houses and the communal lounge, exclude him, and others like him, from participating in communal social activities. Overall interviewees living in sheltered housing were found to be unhappy with the social location of their house. Yet, they felt they needed and valued the support offered by a warden-on-call. Even if they never used the service, it provided tenants with a great sense of security and the ability to live independently (interviewees in non-sheltered housing felt the same about the community alarm, see Section 3.3).

4.2.2 Support Services

The high value placed on the support services available to interviewees in sheltered housing goes some way to explaining the paradox of the majority of interviewees living in sheltered housing wanting to move house (Fig. 4.2), while also stating that they liked living in sheltered housing (Fig. 4.4). When interviewees were asked if they would like to live or like living in sheltered housing, those already living in sheltered housing responded most positively (57%) (Fig. 4.4). When asked why they liked living in sheltered housing interviewees stressed the security and the ability to live independently that was conferred to them by the support services of a warden on call. However, interviewees also noted that they were disappointed by and felt excluded by the barriers that restricted social interaction between tenants. Thus, those interviewees who were wanting to move from their present sheltered house, were ideally looking for a house that would:

- be suitably designed for a wheelchair user;
- have local support services on call; and
- facilitate for positive social interaction.

Fig. 4.4 Interviewees who like/would like to live in sheltered housing by house type



4.2.3 Stigma of Sheltered Housing

The experience of interviewees living in sheltered housing is that certain social and physical barriers inhibit social inclusion. From the outside, interviewees living in non-sheltered housing said they would not want to live in sheltered housing because they felt such housing was viewed as stigmatising, providing for the needy and weak in society, and reinforced negative images of people with disabilities. There were a number of young people in this latter group (living in non-sheltered housing) who had experienced life in sheltered housing, specifically, a MBHA trial flat. The trial flat is available to help individuals decide if they want to and/or are able to live independently. However, this study reveals that the trial flat is partly responsible for perpetuating the negative image that interviewees associate with sheltered housing. The trial flat is located within a closed complex that is entered through a single, communal door. The complex itself is situated within a larger sheltered housing scheme composed of individual houses; yet it appears that the trial flat becomes the kernel, the focus of interviewees' negative perceptions of sheltered housing.

I didn't like the idea of being locked in, I like to be able to open my own front door.
Carol, 28/1/97

The experience of interviewees in this study demonstrates that there is a need for a larger trial house/flat (as the size of the trial flat was also criticised) that is integrated into mainstream housing or sheltered housing, but not situated within a sheltered complex. In addition, service providers should ensure that anyone who is interested in having a trial period away from home are fully informed of all the various housing options available to them.

Presently, sheltered housing is perceived as exacerbating the social exclusion experienced by people with disabilities. This results in many interviewees like Kevin

believing that they could not and would not live in sheltered housing because of the stigma that is associated with it. Furthermore it is recognition that social inclusion for people with disabilities is not going to be achieved by spatially segregating people with disabilities from mainstream society.

> *... for me sheltered housing has the stigma attached to it. 'Oh we're no goin' near that scheme, that's got, its all disabled people'.* Kevin, 2/4/97

However, it should be noted that small scale integrated schemes were found to be popular with interviewees. The study data demonstrates that the clustering of three or four (non-warden linked) wheelchair houses, within mainstream housing, fostered social interaction, with neighbours able to benefit from shared experiences.

> *Yeah, like we all get on well with one another, and if any of us is going through a bad patch we know we can rely on one of the others you know, which is good.* Liz, 13/3/97

> *I think even in my last place where I was, overall they were good, but they were able and always on the go. And I said, 'Now would they understand the same?' You know, and that's a good thing, one good thing about it, because you're able to talk you know, and they understand, it's good.* Lucy, 24/1/97

5. EMPOWERMENT

The report has so far highlighted, first, the role special needs housing has played in facilitating for people with disabilities to live independently, and how the quality of house design could be improved by assimilating smart technology to accommodate people with different needs. Secondly, the importance of assessing the social environment in parallel with house design was stressed as a means to avoid perpetuating the social exclusion people with disabilities have experienced for so long. In addition, and arguably equally important, people need to feel that they are valued, that they are listened to, that they are empowered to make decisions influencing their lives, irrespective of their position in the housing market.

Knowledge on a subject is gained through access to information and through experience, hence knowledge is the foundation upon which decisions can be made. As such, knowledge is a source of power that both service users and service providers have, the difference lies in the ability of the two groups to exercise and use their power. To date the balance of power has been weighted against service users. However, Scottish Homes have acknowledged in their Care in the Community Policy Statement (1998) the importance of empowering service users to 'have choice, flexibility and control in their housing circumstances'. In addition to'recognise the important contribution service users and carers can make to the strategic planning process, ... [and we] will seek to influence our strategic partners and others with whom we work to ensure that this contribution is actively sought and facilitated' (Scottish Homes, 1998, p.18).

This section of the report addresses two sources of knowledge that can lead to empowerment. First, access to quality information, or 'second hand knowledge', and secondly, the ability of service users to utilise the 'first hand knowledge' they have of their own housing needs and experiences. Throughout the report the disparity between social housing tenants and owner-occupiers has been evident, it is no less so in relation to empowerment. It was found that social housing tenants compared to owner-occupiers:

- find it more difficult to find housing information; and
- feel they have little choice, control or power over decisions governing their housing.

5.1 'SECOND HAND KNOWLEDGE'

Scottish Homes has set out in its Care in the Community Action Plan, that by 2001 people with particular needs will have improved access to good information and advice on housing related issues (Scottish Homes, 1998), recognising that '[e]asily accessible advice and information on housing options is essential to ensuring the provision of appropriate housing for all' (Scottish Homes, 1998, p.24). This study indicates that effective communication and access to relevant information remains an area that needs to be further developed (see MacFarlane & Laurie, 1996, Eccles, 1995, Disability Scotland, 1994).

Over 50% of interviewees were found to be experiencing difficulties in either accessing information regarding the adaptation of their house or information on finding and moving to a suitable house. Furthermore, access to information was found to be related to age and tenancy status.

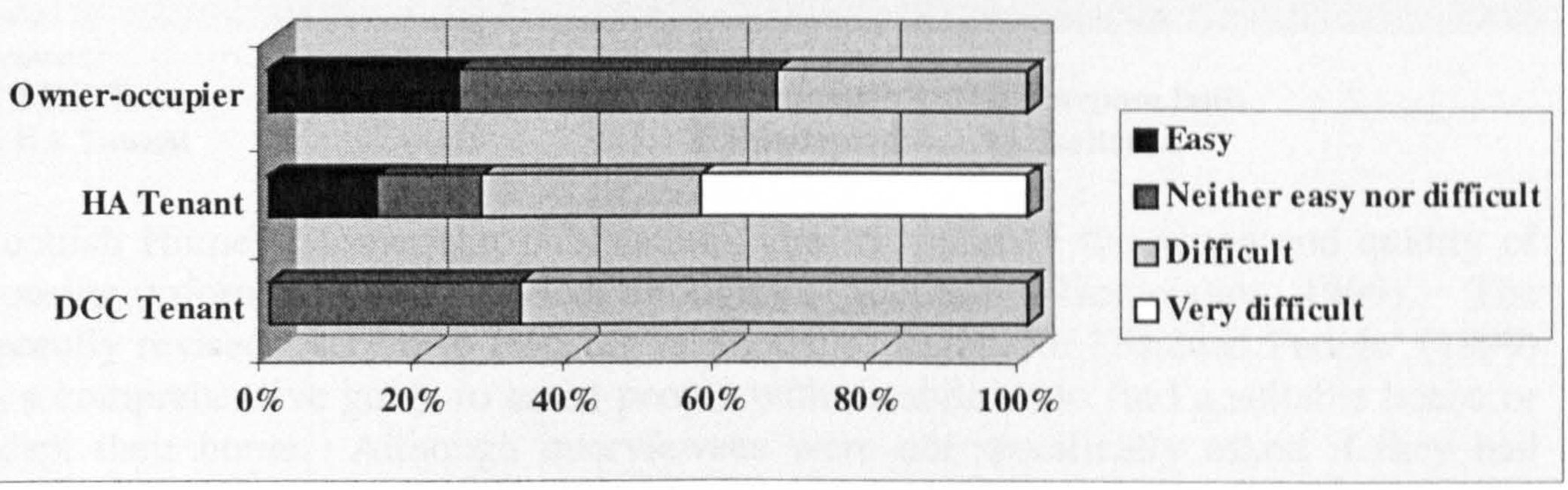
5.1.1 Age

In the 55–64 age group, 80% of people found it 'difficult' or 'very difficult' to find relevant housing information, compared to 33% of 16-24 year olds, 60% of 25-34 year olds and 35-44 year olds, and 23% of 45-54 year olds. (It should be noted that none of the interviewees found it 'very easy' to find housing information). The results suggest a need for service providers to target certain age groups to ensure they have access to relevant housing information.

5.1.2 Tenancy

In relation to tenancy, interviewees in social housing found it more difficult than owner occupiers to find and access relevant housing information. Sixty seven percent of local authority tenants and 72% of housing association tenants found it 'difficult' or 'very difficult' to access housing information compared to 33% of owner-occupiers (Fig. 5.1). For example, many interviewees, who did not have a community alarm, knew nothing about the service, but showed interest in acquiring more information about the service.

Fig. 5.1 Ease with which interviewees were able to access housing information by tenancy



The study suggests that owner-occupiers are more likely to seek information independently and be more successful in finding relevant information. Even so, owner-occupiers emphasised that housing information is not easily acquired and cited inadequate flows of information, between service providers and service users as barriers for people with disabilities to access information on housing issues. As Gail and Zoe (both owner-occupiers) remarked:

> *nobody'll tell you what you can get, you have to shout and shout loudly at the right person, until you get something, and it's wrong, it's so wrong.*
>
> Gail, 30/1/97

> *... when you come home and ask what can I have, they don't tell you. You have to tell them what you need and they'll see if you can have it. It's not the case of what can I have and here it is.* Zoe, 8/12/96

5.1.3 Information Sources

Across all tenancies occupational therapists were found to be the principle source for housing information utilised by interviewees (58%). Owner-occupiers are significantly more likely to use occupational therapists (84%) than other tenancy groups (Table 5.1). In relation to house type interviewees living in mainstream unadapted, adapted and purpose built housing, were more likely to have acquired information from occupational therapists than interviewees in sheltered housing. Sheltered housing tenants had received housing information from a variety of sources, principally: occupational therapists (33%), hospitals (20%), care managers (20%), GP's (14%) and Dundee Council housing department (13%). This suggests that people moving into and living in sheltered housing have more contact with health professionals and care managers than people living in other types of housing (Table 5.1).

Table 5.1 Source of information used by interviewees for acquiring information on housing by tenancy and house type

	A	B	C	D	E	F	G	Total
OT	38%	29%	84%	67%	83%	64%	33%	58%
Care Manager	19%	14%		11%			20%	10%
Hospital	9%	14%		5%			20%	8%
GP	5%	29%				9%	14%	6%
DCC Housing	24%	14%		5%	17%	18%	13%	12%
Own research			8%	6%				2%
Family			8%	6%				2%
Friends	5%					9%		2%
Total	100%	100%	100%	100%	100%	100%	100%	100%

Tenancy
A DDC Tenant
B HA Tenant
C Owner-occupier

House Type
D Adapted
E Unadapted
F Purpose built
G Sheltered

Scottish Homes' Homepoint publications aim to 'improve the scope and quality of housing information and advice throughout Scotland' (Homepoint, 1999). The recently revised 'Access to Housing in Scotland, Rights for Disabled People' (1999) is a comprehensive guide to assist people with disabilities to find a suitable house or adapt their home. Although interviewees were not specifically asked if they had received the Homepoint publication, there is no evidence to suggest that interviewees had access to this or other publicly available guides.

Access to relevant information is a persistent problem for people with disabilities. One approach that has been adopted to tackle the problem has been the development of a 'one-stop shop' for housing information. The Walbrook Housing Association in Derby pioneered the idea of placing all housing information in a single location. The housing service offers general housing advice, advice on aids to mobility, estimates of housing costs and financial advice, information on renting or purchase of accommodation, the provision of individually adapted housing and counselling (Wheeler & Whyte, 1990). There are similar Disabled Person's Housing Services in Sheffield and Lothian and based on the findings of this study there is scope for

developing a one-stop centre in Dundee to meet wheelchair users needs for easier access to housing information.

5.1.4 Helpfulness of Service Providers

Despite interviewees experiencing communication and access to information problems, 75% of interviewees found service providers helpful in their interactions with them. Housing association tenants spoke most favourably about the helpfulness of service providers (Tables 5.2 & 5.3).

Table 5.2 Helpfulness of housing providers by tenancy

	A	B	C	Total
Very Helpful	24%	14%		16%
Helpful	43%	71%	8%	34%
Neither Helpful nor Unhelpful	5%	15%		4%
Unhelpful	14%			8%
Very Unhelpful	14%			6%
Not Applicable			92%	32%
Total	100%	100%	100%	100%

A DCC Tenant
B HA Tenant
C Owner-occupier

Table 5.3 Helpfulness of staff from SWD by tenancy

	A	B	C	Total
Very Helpful	19%	14%		14%
Helpful	48%	71%	83%	62%
Neither Helpful nor Unhelpful	5%	15%		4%
Unhelpful	14%		8%	12%
Very Unhelpful	14%		9%	8%
Total	100%	100%	100%	100%

A DDC Tenant
B HA Tenant
C Owner-occupier

Overall the interactions people with disabilities had with service providers were perceived as positive. However, for many of the 20% of interviewees who were unhappy with their interactions with service providers, their housing situation was also unsatisfactory and distressing.

> *Susan: You said you'd been waiting two years now for a new house, do you think that's a long time to wait?*
> *Penny: Well they're not even helping to even put a temporary ramp, ken. But they dunna care, ken. Like when I first complained there was no toilet downstairs, when I first told them right that I canna get up the stairs, it's really hard, and I'm incontinent, I'm on these water pills and I'm needing to get to the toilet, like they says to me, 'use a bucket'.* Penny, 5/2/97

As Helen points out, there is still much work to be done to improve interaction and communication between users and providers.

> *Susan: What about communication between you and the housing department, do you think that could be improved?*
> *Helen: Yeah, but I think it would take a long time, you've first of all got to break down the barriers and make them realise that you're not just a name on a piece on paper, you're a person. And you've got to make improvements in social contact, when I phone up, because I've got a speech impediment my voice will eventually start to get quieter and quieter, and I think they think I'm not fully composmentis, when they could be more patient.* Helen, 6/2/97

5.2 'FIRST HAND KNOWLEDGE'

Scottish Homes (1998) want their strategic partners to recognise and put into practice the process of consulting and listening to service users. They understand that service users' experience of living with a physical impairment in (in)adequate housing, privileges them to 'first hand knowledge' about their housing needs. Service providers have the power to capitalise on their clients' knowledge to improve their service. Many interviewees recognised the value of service providers talking to people with disabilities as a channel for accessing first hand knowledge, and were disappointed that service providers were hardly utilising this channel of communication.

> *Iris: ... it's like research they're not taking the benefits of what other people have done to help the disabled, so they're starting up with attitudes and ideas and each generation has to get that knocked out of them until understanding is developed before it will actually take on. Even the councils and that are still not aware of what they're doing wrong.*
> *Susan: What do see as the best way of moving forward?*
> *Iris: I think a lot more consultation with disabled people, and really just 'em people like yourself people at the ground you know when you're starting out taking an interest in how they can help, before they go and make mistakes and learn by their mistakes. A lot of people from the department learn from their mistakes, and say "Oh if only we'd known".* Iris 28/1/97

Contrary to the objectives laid out by Scottish Homes (1998) and service providers responsibility to consult with service users (NHS and Community Care Act 1990), this study indicates that social housing tenants feel that they are not being listened to and have little choice, flexibility and control over their housing. Consequently, interviewees expressed feelings of disempowerment, insignificance, and marginalisation in decisions governing their housing. As Alex testifies, questions about her experience of choice, flexibility and control over her housing appear rhetorical.

> *... the thing is they did ask me, but they already had their minds set on what they were to be using. And they just asked me, it was just like, yes we'll let you think that you're going to get that but we're not really going to do that because we've already made up our minds. ... They just ignore disabled people and humour them.* Alex, 11/4/97

5.2.1 Exercising Choice

In the early 1990s Dundee City Council, innovatively and successfully, consulted a handful of prospective disabled tenants before building individualised houses for these people. The tenants that I spoke to, that had been involved in this scheme, felt they had been empowered, included, and their opinions valued. Housing planners and architects had listened to the future tenants needs and put their suggestions into practice.

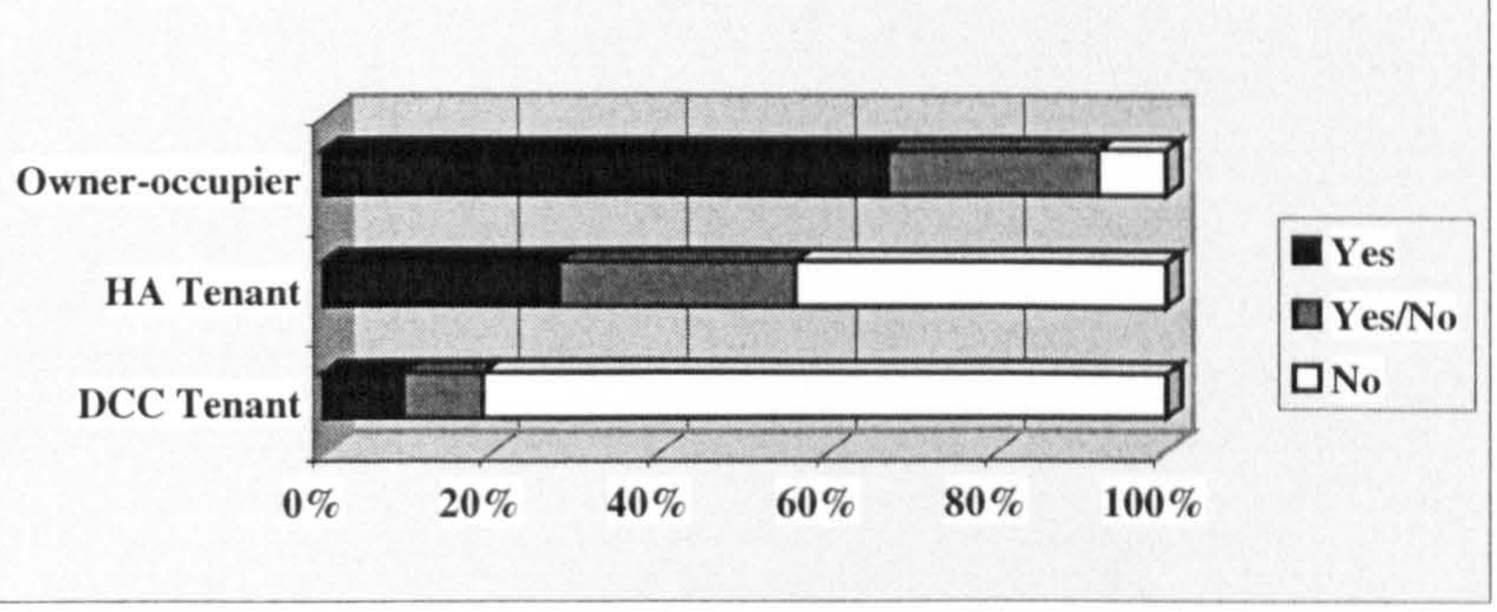
> *[This house] it's been our saving. They asked us, 'em they got five people*

> *with different disabilities, and asked us what we wanted and then they built them. ... there wasn't any plans, they come and seen all of us first like, when we were in other houses like and asked us what we wanted, how many rooms, where would you like your cooker and things like that. And then they built them.* Gillian, 12/2/97

Despite the success of this venture, Gillian doubts whether the council will repeat the exercise because of financial constraints. Hence, she questioned Dundee Council's sincerity in complying with their responsibility to consult with and listen to service users, as required under the NHS and Community Care Act 1990. It appears that Gillian and other local authority tenants who were involved in Dundee Council's innovative, consultative scheme were lucky. For other social housing tenants the scenario is very different with regard to their involvement in decisions governing their home (Fig. 5.2).

The government recognises 'that people who become involved in managing their own housing often find it an 'including' experience in itself, and are then able to build on that experience to participate more widely in community life' (Scottish Office, 1999). The Scottish community-based housing association movement is adopting this philosophy as it seeks to empower local people through involving them in decisions influencing their housing.

Fig. 5.2 Interviewees who felt they were involved in housing decisions by tenancy



The findings summarised in Fig. 5.2 point to the disparity between owner-occupiers' involvement in decisions influencing their house and social housing tenants' involvement. For owner-occupiers, like Gail, who want to adapt their house, they feel in control of the situation and their interactions with service providers. In contrast Penny, a local authority tenant, feels that the limited choice she has with regard to her housing is a consequence of her being disabled.

> *I was able to make my ideas known, but also I'm sensible enough to take advice, if what I was getting done wasn't going to be good enough for what might be in the future.* Gail, 30/1/97

> *I remember I was down at the office (DCC Housing Dept.) and they'd put Ardler or something down and I says, I never asked for that. And they says, you can't have it otherwise, you've got no choice. Because it's disabled you've not got any choice. And so really it's your life, if you're disabled,*

> *you've not got any choices, you canna decide what you want, and you've just got to put up with what everybody else wants.* Penny, 5/2/97

Penny has resigned herself to the fate of being disabled and hence she feels like a 'second class citizen'. This misperception is based on the assumption that an individual's capacity to participate fully in society is related to his/her (dis)ability. This approach places the onus on the individual to overcome their physical impairment and conform to the able-bodied majority. The philosophy of the social model of disability and the language of social inclusion challenge such ideas by placing the responsibility and ability to eliminate the barriers that have marginalised and excluded people with disabilities onto society. The onus for tackling disability is shifted from the individual to society: to policy makers, service providers, and society's attitudes, working in partnership with people with disabilities. As this study demonstrates there is a long way to go to eliminate the disparities in the housing experiences of people with disabilities, primarily based on tenure and house type. To diminish this disparity service providers need to facilitate the expression of housing needs by social housing tenants and to incorporate these needs into housing practice. Thereby people with disabilities will be empowered and can begin to exercise choice and control over issues affecting their homes.

6. CONCLUSION AND RECOMMENDATIONS

Community care was heralded as opening the door for people with disabilities to lead more independent lives as integrated members of their local communities. Yet, as this study illustrates people with disabilities are experiencing social exclusion, they feel marginalised and disempowered in decisions governing their housing, both of which are exacerbated by an inadequate supply of suitably designed dwellings. Current interest by politicians and housing practitioners in social inclusion and empowerment has reinvigorated the debate on ways of integrating marginalised groups (community care and non-community care groups) into their respective communities.

This qualitative study has demonstrated the pivotal role housing plays in the experience of social inclusion or exclusion in the lives of people with disabilities. In particular, two key themes have emerged from the results of the study: the impact of tenancy and location on an individual's housing experience. The disparity between social housing tenants and owner-occupiers has demonstrated that:

- housing association tenants, despite living in houses that are architecturally superior for wheelchair users than local authority and owner occupied houses, are less likely to feel included in their local communities;
- owner-occupiers are better able to diminish their experience of social exclusion through voluntary intra-urban migration and/or adapting their house; and
- owner-occupiers have greater choice, control and power over their housing then social housing tenants.

An objective of the Scottish Executive and a guiding principle behind the work of Scottish Homes is to 'enable people with particular needs to lead lives as close as possible to those of other tenants and owner-occupiers' (Scottish Homes, 1998). The recommendations that emerge from this study are made as a contribution to tackling the present disparity in housing experience across tenancies.

6.1 RECOMMENDATIONS

House Design

- There is scope for incorporating smart technology into the re-design of windows, doors and kitchens in wheelchair users housing.
- There is a demand for more two-bedroom dwellings for wheelchair users.

Social Inclusion

- Service providers could be more aware of the locational needs of their clients when allocating housing, for example, the proximity of a house to friends, family, carers, shops and the city centre.
- Service providers could diminish moves by social tenants that exacerbate social exclusion by:
  - broadening the information they offer prospective tenants;
  - allowing more time for house visits; and
  - offering the choice of additional house visits if requested by the client.

- ❖ If sheltered housing is to accommodate young people it must be able to meet their social as well as their physical housing needs.

Empowerment

- ❖ Social housing tenants need to be offered greater choice, control and flexibility over their housing.
- ❖ Access to relevant housing information must be improved for people with disabilities generally, and social housing tenants and the over 55s, specifically.

6.2 EXTENDING THE STUDY

This report is targeted at policy makers and housing practitioners as a medium for communicating the knowledge and understanding people with disabilities have of their housing needs. The report is being sent to key housing practitioners and the interviewees who made this study possible. As part of the ongoing research process recipients of the report have been asked to comment on the findings presented to them.

The results of this study provide a valuable insight into the housing experiences of wheelchair users living in different types, tenures and locations of housing in Dundee. Weaknesses in Dundee's ability to meet the holistic housing needs of its disabled population have been highlighted. However, the results of this study relate specifically to the experiences of wheelchair users in Dundee in the late 1990s. For planning and policy purposes it would be beneficial to evaluate the uniformity of the findings across Scotland. Hence, there is scope for applying the methodology used in this study to other urban and rural areas in Scotland. For as Alex says,

> *I think it's very good that you're doing it, when I first saw your letter I went, look, someone is doing something. People might read it and see people in wheelchairs aren't happy with their housing, they're not!* Alex, 11/4/97

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